Pathways to diagnosis and treatment: TB patients' experiences in London.
A Narrative Enquiry and Analysis

The thesis

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Declaration Statement of Original Work

I, *Lemma Yilma,* confirm that the work presented in the thesis is my own. To the best of my knowledge the thesis is original work and does not contain any other student or person research work or idea. Where information has been derived from other sources, I confirm that this has been acknowledged and referenced in the text of the thesis.

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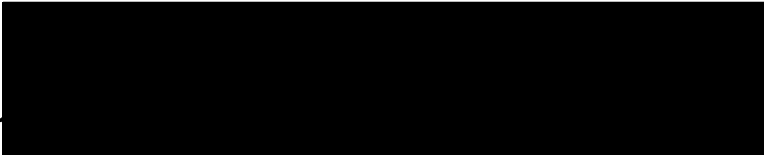
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ABSTRACT

The purpose of this study was to understand TB patients' experiential accounts of access to TB diagnosis and treatment and more specifically about their experiences of medical help from health care professionals.

METHOD: This narrative enquiry was undertaken in three boroughs of London, including two boroughs with the highest TB notification rates in the UK. The study involved pilot interviews with ten patients to develop the research question. In-depth narrative interviews with 32 additional patients were then undertaken. All participants were over eighteen years of age. The analysis of narratives involved descriptive; holistic-form and categorical content (themes) approaches to identify story 'plot' and 'subplots' and themes covering the whole of the patients' journeys to treatment.

RESULTS: Seven narrative plots and thirty subplots were grouped into six categories of medical help and specific themes embedded in them were grouped in three stages of patients' pathways 'before' 'during' and 'after' diagnosis. These themes are listed below sequentially to illustrate these patients' pathways. 1. Symptoms were misinterpreted and misdiagnosed. 2. Kept on ineffective antibiotics/painkillers for many visits. 3. Referred quickly for suspected TB or other serious illnesses. 4. Referred only when critically ill. 5. Referred when antibiotics and pain killers not helping. 6. Referred only after pushing for referral. 7. Sought help from A&E. 8. Diagnosed immediately after TB testing. 9. Referred to wrong specialist and waited too long. 10. Had to fight for TB test. 11. Had lots of tests but no results. 12. Doubts about diagnosis. 13. Felt ignored and had no information. 14. Felt listened and cared for. 15. Quickly began my treatment. 16. Felt better after treatment, no side-effects. 17. Felt better after treatment with side-effects. 18. Felt needed longer treatment.

CONCLUSIONS: The accounts of two thirds of the study participants suggest that their doctors' misunderstanding of their illness and miscommunication with them contributed to delayed diagnosis and treatment ranging from one month to twelve months. TB service providers and commissioners need to raise clinical staff awareness about TB and review the factors hindering doctor-patient communication about TB care. The findings in this research indicate that health service related delay is likely to contribute to increased TB transmission rates in the two research settings in London.

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ACRONYMS

A&E -   Accident and Emergency

A&E -	Accident and Emergency
AIDS -	Acquired Immunodeficiency Syndrome
BCG -	Bacillus Calmette Guèrin vaccine
CAB -	Citizen Advice Bureau
CCDC -	Consultant for communicable disease control
CMO -	Chief Medical Officer
CT scan -	Computerized Tomography Scan
DH -	Department of Health
Dr PH -	Doctor of Public Health
DOT -	Directly Observed Treatment
Dx -	Diagnosis
EB -	evidence-based
ENT -	Ear Nose and Throat department
GP -	General Practitioner
HC -	Health-Care
HPA -	Health Protection Agency
HO -	Home Office
HCC -	Health Care Commission
HPU -	Health Protection Units
HCC	Health Care Commission
HSC	Health Select Committee
HIV -	Human Immunodeficiency Virus
LSHTM -	London School of Hygiene and Tropical Medicine
LA -	Local Authority
METRO -	London News Paper
MDRTB -	Mono-drug resistance TB
NUTH -	Newham University Teaching Hospital
MUTH -	Middlesex University Teaching Hospital
M.Tb -	Mycobacterium Tuberculosis
NECL -	North East Central London
NES -	Non English Speaking
NHS -	National Health Service
NICE	National Institute of Clinical Excellence
NCCCC	National Collaborating Centre for Chronic Conditions
NRES -	National Research Ethics Service
NP.Tb -	non-pulmonary tuberculosis
PCT -	Primary Care Trust
P.Tb	pulmonary tuberculosis
PA -	Professional Attachment
Pt. -	Patient
REC -	Research Ethics Committee
Rx -	Treatment
RLH -	Royal London Hospital
RCP -	Royal College of Physicians
REC -	Research Ethics Committee
SECL -	South East Central London
SWCL -	South West Central London
TB -	tuberculosis
TST -	Tuberculin Skin Test
XDRTB -	Extra drug resistance TB
WC -	Walk-in Centre
WHO -	World Health Organization
X-ray -	Radiographic test for TB

ACKNOWLEDGEMENT

Introduction and Thesis Overview

This research explores the experience of TB patients' pathways to TB diagnosis and treatment in London. While TB patients' barriers to diagnosis and treatment is related either to patients or providers of care (*the protagonists*), it appears that research in London only provide a partial understanding of the patients' experiences. The thesis' main aim is to fill this gap in knowledge about the research phenomena from patients' stories of their experiences of events leading to diagnosis and treatment.

This makes a particular contribution to the current Department of Health (DH) emphasis on NHS patients' experiences of care delivery from primary and secondary care providers (DH, 2007b). In the arena of TB policies, patients' experiences of service delivery are key to TB service commissioning (DH, 2004) and care delivery, underpinned by a patient-centered care model (NICE, 2006). However, many of the dominant stories (master narratives) are centered on demographic differences of patients in accessing TB services, rather than their experience of health care provider associated barriers to diagnosis and treatment. On the one hand this body of knowledge focuses researchers' attention on gender and ethnicity differences (Rodger et al. 2003), type of TB associated with delay (Lewis et al. 2003) and migration and birth place differences (Paynter et al. 2004). Furthermore, delay associated with health services was found to be associated with long referral procedures to specialists and diagnostic facilities (Paynter et al. 2004). However, evidence drawn from these studies is based on surveillance data and providers' accounts rather than patients. On the other hand, there is dominant thinking that social condition, involved in living in poverty and stigma with TB, lead to delay in seeking care for diagnosis and treatment (HPA, 2006b). However, much evidence on poverty and stigma impact on TB appears to overlap with the complex barriers associated with lack of timely access to diagnosis and treatment. Evidently, there is much diffused knowledge surrounding barriers to diagnosis and treatment due to the lack of empirical knowledge from patients' experiences. This research involved listening to retrospective accounts of forty-two patients' experiences of events leading to diagnosis and treatment in London.

I argue that the dominant stories (master narratives) in my review appear to put little emphasis on the multitude of factors associated with healthcare pathways to diagnosis and treatment. As a result, the patients' demographical differences rather than factors associated with providers of care have become a focus of researchers' attention. I contend that the reality of knowing factors associated with the patients' healthcare seeking phenomenon is intrinsically linked to patients' experiences of care settings and this is the focus of my thesis and the research questions.

The thesis research question has sought to understand the participants' experiences of medical help in London and more specifically their experiences of healthcare professional support. The study is called a *narrative enquiry* on TB patients' experiences of pathway to TB diagnosis and treatment in London. The thesis provides the representation of forty-two patients' stories divided into eight thesis chapters in the following way: In Chapter one, I present the background to the research in two sections. In the first section, I present a brief background of research context, the statement of the research problem and the research questions. In the second section, I specifically define the epistemological and philosophical basis of *'narrative enquiry'* and the conceptual lens it draws from. I also provide an outline for key research terms used to provide background understanding to the research context.

In Chapter Two, the review of literature sections include my search strategy for literature, categorizing the review of the topic into two master narratives, critiques of the literature and a discussion of the use of a narrative approach and its contribution to knowledge.

In Chapter Three, I set out the methodology and the method applied in the operation of the study. I describe the research settings and summarize the pilot research findings. I explain the justifications and rationales of the method. I discuss the framework applied to collect and analyse data. I include why the analytical methods have been chosen for answering the research question, the quality assessment tools and limitations of the method are also detailed.

In three Chapters I present the results and analysis of the data. In Chapter Four, I provide a descriptive analysis (*descriptive explanation*) of stories adapting Emden 1998 guidelines to identify story 'plots and sub-plots'. In Chapter Five, I present a holistic analysis of plot forms (*global analytic explanation*) of stories based on Lieblich et al's holistic form analysis of core stories. In Chapter Six, I take further the descriptive data in more explanatory analysis (*themal analytic explanation*) using Lieblich et al's categorical content (categorical themes) analysis of story plots and subplots. In Chapter Seven, I present the discussion of integrated findings and main themes highlighted in participants' stories about their medical help experiences. At the end of each Chapter, I provide a summary of the findings.

In Chapter Eight, I will end with conclusions, reflections of the research questions, research processes, limitations, study findings and key recommendations for policy, research, practice and dissemination of research findings.

Chapter One   Background and Research Context

1. Background of the study

Mycobacterium tuberculosis *(M.Tb)* – causes the human form of TB illness – one of the major killers for many generations and still one of the three global public health threats, *(HIV/AIDS; TB; Malaria),* (Bates et al. 2004 a & b). After steady decline in incidence for about three decades, TB began to re-emerge particularly in the UK and other developed countries in the late 1980s. A number of factors were attributed to its decline from the early 1900s. (see Fig 1 below) On the one hand, it was argued that post industrialization and affluence, better living and life-style, good nutrition, better housing (McKeown, 1962 - cited in Colgrove, 2002:p.725) and sanitation, public health measures and better social intervention (Szreter, 1988 - cited in Colgrove, 2002:p.727) had contributed to its decline. On the other hand, innovation in bio-medical sciences, better knowledge about TB epidemiology, effective chemotherapy with the drug isoniazid have been causally linked to the decline (McDermott, 1980:p.128-9). These historical accounts are useful concerning TB and how we may have perceived it today. In the UK at least, the steady decline after the 1950s has brought about the sense of feeling that TB is no longer a threat and the perception amongst the general public that TB is a problem of the past rather than here in the present.

Figure 1 Tuberculosis notifications, England and W ales, 1913-2009
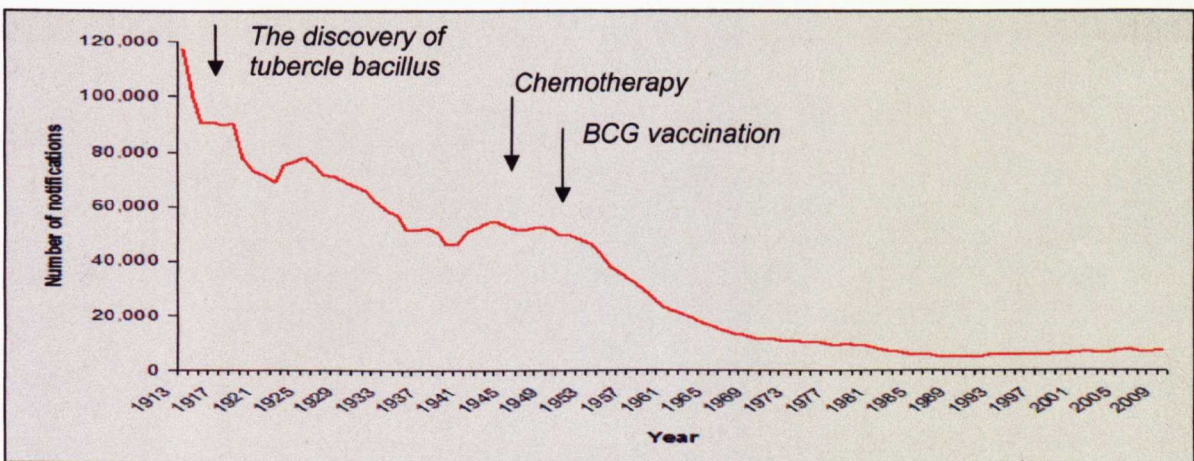
Source: PHLS CDSC – HPA Cfl Colindale London

In 2009, there were an estimated 9.4 million incident cases (range, 8.9 million–9.9 million) of TB globally (equivalent to 137 cases per 100 000 population). Of the 9.4 million incident cases, an estimated 1.0–1.2 million (12%) were HIV-positive. There were an estimated 14 million prevalent cases (range, 12 million–16 million) of TB in 2009, equivalent to 200 cases per 100 000 population. An estimated 1.3 million deaths occurred among HIV-negative

cases of TB, including 0.38 million deaths among women. This is equivalent to 20 deaths per 100 000 populations (WHO 2010: p.5 -7).

The highest incidence of TB has been reported in sub-Saharan Africa and Asia and western pacific regions and accounted for 83% of total case notifications (WHO 2008: p.3). Unlike TB of the past, the re-emergence of TB in the 1980s has been associated with new emerging infectious disease; HIV/AIDS, increased in prison populations, homelessness, injections drug use, crowded housing (Palomino et al. 2007: p.45) and increased migration from countries where TB continued to be endemic (Palomino et al. 2007: p.45; Davies et al. 2002:p.1646; Reider et al. 1994).

In the UK, the incidence of TB has been rising since 1988 with more cases of pulmonary TB than the non-pulmonary form of TB, (HPA, 2009). The highest increase was in non-UK-born cases which accounted for 73% (75% per 100,000) of total cases, most born in sub-Saharan Africa and South Asia (HPA, 2010:p.10-13). Furthermore, the rate (disease pattern) in the UK-born black African and Indian/Pakistani/Bangladeshi ethnic populations is also rising more than in other ethnic populations (HPA, 2010: p.13). Every year there are nearly 9,000 new cases of TB notifications and around 473 TB related deaths were reported in 2008. The evidence base from molecular studies in London on sources of TB transmission appeared to produce inconsistent findings, either associated with risk of recent local transmission in inner London (Hayward et al. 2002) or increased risk largely caused by reactivation of latent TB or importation of TB in recent immigrants (Maguire et al. 2002). However, in 2008 there were 8,665 new cases, a 2.2% annual change from the previous year. In 2009, there were 9,153 new cases, 5.5% annual change (increase) from 2008 (HPA, 2010: p.7).

Figure 2 Three-year average TB case rates by primary care organisation*, UK, 2006-2008
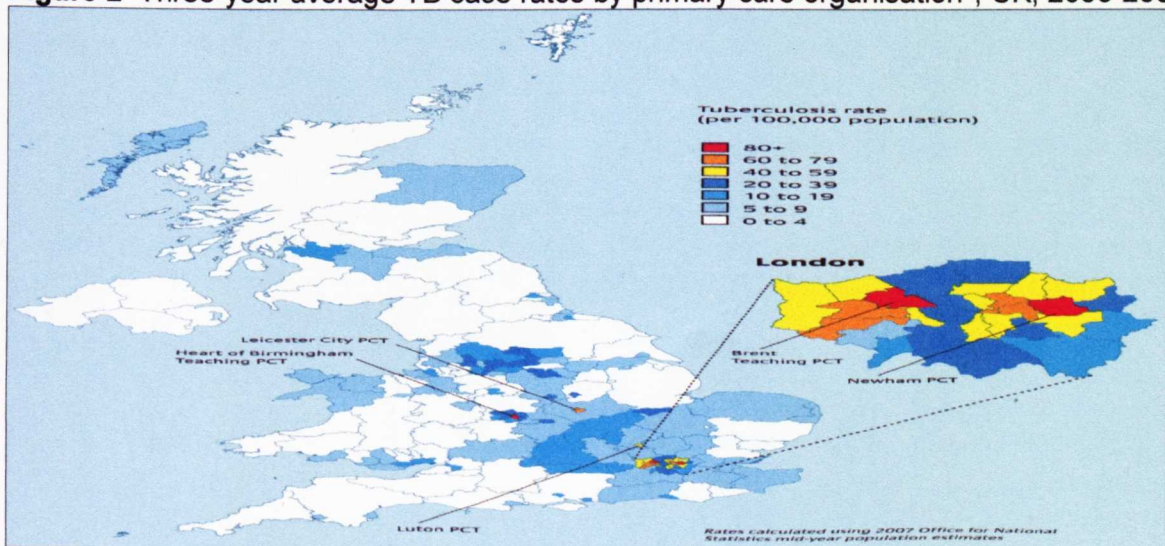
Source: HPA TB report 2009

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London accounts for the highest rates of TB notifications when compared with the rest of the UK. (see Fig 2 above) The steady growth has been the highest in London particularly in some inner London boroughs (HPA, 2010: p.40) where TB notification rates are similar to amongst the highest TB prevalent settings in the world, (WHO, 2010: p.5-6). The recent TB surveillance data from the HPA indicates London accounts for nearly 44.4% (rate per 100,000population) of TB notification rates in England as a whole (HPA, 2010: p.7). In London the rate is higher in non-UK-born which accounted for 84% (103% per 100,000) of total cases (p.12). The situation in London reflects the global epidemiology of TB with the disease pattern more in deprived inner city areas with higher notification rates amongst African and south Asian ethnic population.

Furthermore, in London the TB notification rates have been showing a steady growth year on year, with no sign of decline (HPA, 2007a). TB and HIV co infection rates in London are estimated to be as high as 17-25% in the capital, (Marshall et al. 1999; Bowen. et al., 2000) and most reported cases are within the black African ethnic group (Rose et al. 2002; Anderson et al. 2007). In London, the proportion of tuberculosis cases with drug resistance is half of all cases of drug resistance in the UK with high levels of isoniazid resistance in particular and 40% of multi-drug resistance (MDR) TB cases are in London (HPA, 2009). The proportion of MDR cases was higher in non-UK born with previous history of TB (HPA, 2008: p.16). The concentration of TB in marginalized communities in London has been part of the headline news articles that stir up a sense of public unrest, misconceptions and controversies about TB and migration. Interestingly, a study in Westminster found the African migrant TB patients felt they were being blamed and stigmatized for "*importing*' and '*spreading*' TB by some TB service providers" (Marais, 2007: p.31). In the last two decades; port entry TB screening activities at UK mainland ports has increased substantially.

As Craig (2007a) notes, "anxieties about the risk of imported infection are reflected in the discourse of the 'foreign-born' and calls for the screening of new entrants to ensure health security" (p.268). Whilst the challenges still remains to finding better ways of engaging with population at risk of TB, as Craig notes, 'the inscription of risk groups and discourses of (im)migration, which reinforce the idea of imported infection...contributes to the very stigmatization of the disease public health seeks to dismantle through technologies of risk" (2007a:p.271). In view of these issues, it is useful to touch on some of the macro–level policy literature in public health and TB research.

1.1   TB policy and research

The 'Stopping Tuberculosis in England' (DH, 2004) - CMO report is one of the key publications containing national TB action plans that set a policy framework for national and

local TB control in England. In 2006, the National Institute of Clinical Excellence (NICE) formulated a guideline - its core philosophy *Patient-Centred Care*[1] which emphasises that 'treatment and care of people with, or at risk of contracting TB should take into account patients' individual needs and preferences' (NICE, 2006: p.6).

A number of useful recommendations have been included in these publications of which the most dominant themes are: (1) public education about TB, (2) improving fast access to TB services, (3) patients' experiences as part of local service design and delivery, (4) patient-centred care - improving patients' experience through 'supportive clinical pathways, (5) providing culturally appropriate/accessible information and care, widening access to primary care, (6) a family and patient-centred care policy, (7) integrated care services with strong link to the local community (DH, 2004). More recently, the DH health care policy guidance 'Ensuring Better Care for All', the DH Strategic policy framework, also states each individual's judgement of their experience of medical help and care has a unique basis and depends on many aspects of their care. An "individual's judgement of their care is considered to involve factors such as service: accessibility, timeliness, quality, safety, effectiveness, dignity, respect, meeting expectations, and sensitivity to personal needs" (DH 2007b: p.9).

The Health Protection Agency (HPA) produced the '*Migrant Health Report*' – with key recommendations for the implementation of NICE guidance and also recommendations for research on the impact of poverty and social conditions on access to early health care by patients (2006b:p.43). Moreover, in 2006 the DH and NICE commissioned evidence-based guidelines published by the Royal College of Physicians (NCCCC-RCP, 2006) which states its recommendations for research priorities to address the lack of evidence base in relation to diagnostic and treatment delay and to identify how to shorten the period of infectivity of active cases (p.194).

In relation to the increasing TB notifications rate amongst foreign-born subjects, the DH reinforced its policy guidance on port entry screening for migrants entering the UK from high-risk areas, particularly for those who intend to stay in the UK for over 6 months (DH, 1992). Despite its merits, this policy has been criticized for lacking evidence-based scientific rationale, particularly using chest X-ray on asymptomatic migrant population which generates a huge workload for TB services, (Hogan et al. 2005) diverting resources from frontline TB services. Coker (2003) points out the medical, ethical and legal dilemmas

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[1] **Patient-Centred Care:** in general terms "is a process by which a health care professional (a)explores the patients' main reason for the visit, concerns, and need for information; (b) seeks an integrated understanding of the patients' world- that is, their whole person, emotional needs, and life issues; (c) finds common ground on what the problem is and mutually agrees on management; (d) enhances prevention and health promotion; and (e) enhances the continuing relationship between the patient and the health care professional." (in Smith and Ross, 2004: p.11, see also Kreps and O'hair, 1995: p.91).

involving the port entry screening policy for public health practice and suggests a welcoming check by primary care to new arrivals, rather than port-entry screening tests which is unscientific in its approach, (p.31-3). Similarly, the HPA advised DH on the need for integration of TB screening as part of NHS primary care functions to implement the NICE guideline (HPA 2007b). Several research projects have been commissioned to evaluate the benefit of active case finding using the port entry system and most research found poor yield from the port entry system (Callister et al. 2002; Hogan et al. 2005; Millership et al. 2005; Underwood et al. 2003). Despite this, there is compelling evidence on more effective TB control by reducing barriers to treatment and enhancing capacity to early detection (WHO, 2005). Neither the port entry policy nor evaluation research provides sufficient understanding of current pathways to TB diagnosis and treatment. Beyond the research focus on port entry evaluation, some epidemiological studies in London have actually looked at barriers to delaying diagnosis (Rodger et al. 2003; Lewis et al. 2003; Paynter et al. 2004). None of these studies however engaged with patients to understand pathways to TB diagnosis and treatment and barriers to delay. The limitations of surveillance data have been stated in the HPA report (HPA, 2006b:p.37-43). This relates to the research focus on population demographics, clinical data and disease pattern in populations, rather than understanding 'illness' pathways and patients' experiences and their descriptions of day-to-day life with the disease. For instance, the DH patient experience statement highlighted that most NHS patients felt they were treated like a number, not as an individual. Their emotional needs often were not met at times when they were most vulnerable, (DH, 2003: p.9). Moreover, over the last decade, NHS care policies have become increasingly receptive to patients' experience issues and factors, (DH, 2007b). There is a general interest in health policy to consumers' behavioural factors, users' perspectives and experience in quality health care provision (Muela-HS et al. 2003: p.3).

1.1.1 Statement of the problem

Despite wide policy initiatives to understand patients' experiences of health care delivery, no researcher on TB has yet seriously engaged with patients to understand their experiences of pathways to services in London. A recent review undertaken by Storla et al (2008) involving observational studies from 54 countries included two of the UK studies. The reviewers note that the Lewis et al's study in London reported the second highest diagnostic delay by patients (median 63 days) next to Romania (median 67 days) and delay associated with the providers of care (35 median days) ranked the 10th highest provider delay documented by the reviewers. Delaying contact with health care over 60 days by the patient counted as

patient-delay. Whereas delaying over 30 days from the patients' contact to healthcare to starting TB treatment constituted the provider-delay (Storla et al. 2008: p.9).

The evidence base from research in London on barriers to diagnosis and treatment produces inconsistent findings. For example, amongst these studies diagnostic delay was associated with being white and female (Rodger et al. 2003); persons with extra-pulmonary TB rather than pulmonary TB, (Lewis et al. 2003); being migrants from high prevalent countries, and common amongst patients who sought care from GPs rather than the A&E 'health service delay' (Paynter et al. 2004.). Rodger et al's study (2003) was based on surveillance data collected by doctors. In the Lewis et al's 2003 study, data was gathered from clinical records. Paynter et al's (2004) study applied prospective surveys of GPs to estimate delay in diagnosis. Although the studies' findings are useful in highlighting the magnitude of diagnostic delay in London as a problem per se, the strength of evidence can be questioned on the accuracy of data from clinical records, clinicians' accounts and from surveillance data sets.

A study in south east Wales has documented evidence on health service related factors in delaying pathways to diagnosis and treatment. These researchers found miscommunication and misinterpretation of TB associated with low suspicion of TB by GPs, adversely hindering patients' access to diagnosis and treatment (Metcalf et al. 2007). The findings from these researchers is useful because it highlights the potential problems associated with doctors' accounts and clinical data of the Lewis et al's (2003); Rodger et al's (2003) and Paynter et al's (2004) findings. It is likely that some index TB cases may have already contacted healthcare and subsequently been diagnosed with other illnesses and counted as delayers, relating delay to the patients rather than to healthcare providers. One qualitative study in London explored the African-born TB patients' perceptions and experiences of TB. These researchers have found factors such as misconception about TB aetiology, symptom misinterpretation and denial of diagnosis and identify misinterpretation of TB symptoms by patients as reasons for reported delay up to forty weeks before diagnosis (Nnoaham et al. 2006). However, in their article, the extracts of three patients interviewed highlights that misinterpretation of symptoms by their doctors accounts for diagnosis delay 4, 10 and 16 weeks respectively. Although this was conspicuously missed in their reporting of delay associated with provider of care, themes inducted seemed not to have been fully explored which could have been more informative of the misinterpretation of TB symptoms by the doctors.

Evidence from studies in the UK present different sets of results, the reason being that evidence from surveillance data, providers' records and clinicians' accounts appear inconsistent with qualitative research findings gathered from patients. This suggests that a better way to understand barriers to diagnosis and treatment associated with

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miscommunication and misinterpretation of symptoms by clinicians is to learn from the patients' stories, based on their accounts of events they have experienced.

1.1.1.1 Why do we need patients' accounts?

In the last few years there has been media interest in stories that attract headlines and a number of stories of patients reverberated throughout the media revealing problems associated with failures of healthcare providers. For instance, the headline of a local newspaper highlighted the stories of two young pulmonary TB sufferers, Amy McConville age 25, a law student; and Carl Liebel age 24 an investment banker in London (METRO, March 5 2007). These young TB sufferers narrated that, despite many months of contacts with their GPs, they were unable to obtain diagnosis and treatment due to their GP's failure to diagnose the typical TB symptoms they were presenting. In the case of Amy, her TB had advanced to cause severe damage to her left lung which was eventually removed by surgery. In the case of Carl Liebel, his story also reveals that, despite many contacts with his GP and receiving treatment with antibiotics for laryngitis, he was unable to get better and was getting worse. It was his father who had advised Carl to travel home (to Australia) where he was able to obtain the correct diagnosis.

Furthermore, there were cases of court litigations against providers of TB services in London. This involved clinical negligence associated with either failure to diagnose and start TB treatment or to manage TB treatment safely for the patients. A brief account of three rather sad stories I have extracted from articles may also underline the version of patients' stories that already highlight problems. (i). Case 1, a 38 year old with tubercular meningitis who alleged her doctor failed to diagnose her accurately and treat her, which had led to irreversible neurological damage and severe disability, (Mead 2006: p.167). (ii). Case 2, a 68 year old Somali man whose death was attributed to his doctor's failure to diagnose tubercular meningitis, (Branley 2009: p.251). (iii) Case 3 - a 43 year old female intravenous drug user, a smear +ve pulmonary TB case, had died from liver failure following hepatotoxic reaction to anti tuberculosis treatment in London. She had viral hepatitis (B and C) contra indicated to some tubercular treatment, (Branley 2009: p.251) and that was obviously unchecked before her treatment. What is implicit in these stories is that pathways to diagnosis and treatment are complex and may not be captured using pre-set questionnaires, surveillance data and clinical records. This is the benefit of qualitative research that seeks to engage with the patients and understand the experiential accounts of their healthcare as reflected and understood by themselves.

I would also like to acknowledge that the type of research method and data collection is determined by researchers' epistemological orientations (what research has sought to find

out or obtain knowledge about). Although this may partly explain the gaps I have highlighted, it is also necessary to explain about what and how I sought to find out from this research general and more specific research questions that relate to stated problems.

1.1.1.2   Research Questions

The thesis research questions are: *What do patients say about their experiences of pathways to TB diagnosis and treatment? How do they tell their experiences of pathways to diagnosis and treatment? What do they say specifically about their experience of medical-help from health care professionals?*

1.1.1.3 How they relate to the public health problem?

These questions have relevance to the TB policy which seeks to improve TB patients' experiences of diagnosis and treatment. Firstly, *the "Stopping TB in England"* recommends that TB patients' views be taken into account when designing pathways to TB services by care providers, (DH 2004: p.19). Secondly, at the end point of service delivery, the NICE clinical guidance recommends clinicians deliver a patient-centred care model, (2006: p.6). However, since the publications of these documents, little is known about TB patients' accounts of their healthcare, particularly in London. It is almost four years since the NICE report made recommendations for research evidence on delay associated with pathway to diagnosis and treatment, (NCCCC/RCP, 2006: p.194) and problems associated with providers of care in London are not fully understood.

There is a tendency for studies in London to assume patients are the primary source of delay in seeking healthcare in time. None of the studies in London focused on their research to identify patients' experiences of the complex pathways involved in accessing diagnosis and treatment. The purpose of this research is to understand and contribute to gaps in knowledge concerning patients' experiences of their healthcare by TB service providers in the London.

1.1.1.4 The Research Definition

In order to clarify the research conceptual lens applied in this research, it is necessary to define this research and its meaning. First, I present below some definitions used by others to define the meaning of *'research'* as:

1. *"a systematic, formal, rigorous, and precise process employed to gain solutions to problem and or to discover and interpret new facts and relationships." (*Waltz & Bausell, 1981).

2. *"the process of looking for a specific answer to a specific question in an organized, objective, reliable way"* (Payton, 1979).
3. *"a systematic, controlled, empirical, and critical investigation of the natural phenomena guided by theory and hypotheses about the presumed relations among such phenomena"* (Kerlinger, 1986), (cited in Fawcet and Downs 1992: p.3).

Fawcet and Downs have made important distinctions between these three definitions in their publication. They saw the first definition by Waltz & Bausell (1981) as less restrictive and non empirical[2] but as a rigorous problem-driven approach to a research. The emphasis is on problem solving rather than answering a specific research question. The definition by Payton (1979) however was deemed restrictive because it does not give emphasis to subjectivity and may imply pro quantitative rather than qualitative research. As to the third definition, Fawcet and Downs state that Kerlinger (1986) definition is also restrictive, but empirical in its approach. The reason they have given was that it only referred to a deductive theory testing research rather than an inductive one. Qualitative research is of course an inductive research and deals with subjective data.

These definitions in some ways help to define this research and also to reflect on how this research provides answer to the research questions and how it differs from other researchers' work. It is in this process that I was able to identify a definition that suits my research. I therefore define my research as "a narrative enquiry through in-depth interviews with TB patients in naturalistic settings in order to understand and make sense of their experiences of the phenomenon in terms of the meanings people bring to it" (Denzin and Lincoln 2000: p.3). This definition also relates to the conceptual lens applied in this research.

1.1.1.5   The Research Conceptual Lens

In social research, there are differing philosophical and epistemological[3] bases that underpin what and how researchers seek to explore research problems, questions and learn about the research phenomenon. Crotty (1998: p.8), has classified three epistemologies of social research as: objectivist; constructionist; and subjectivist epistemologies. An objectivist epistemology holds that meaningful reality exists independently of any human

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[2] *Empirics:* are kinds of theories, and scientific researches (mode of inquires), that characterize factual descriptions, explanations or predictions based on subjective or objective group data. They are publicly verifiable and discursively written as scientific theories. Empirical theories generally are classified as descriptive, explanatory or predictive. Empirical researches are the scientific research designs that gemnerate and test these types of theories are called descriptive, correlational and experimental, (Fawcet and Downs 1992, p.6-7). A research is defined as non empirical if it does not relate to an empirical theory or a concept and if it is not designed to generate or test a theory or concept.

[3] *Epistemology* is a theory of knowledge – and deals with the nature of knowledge, its possibility, scope and general basis, (Hamlyn 1995 – cited in Crotty 1998: p.8). It is concerned with providing a philosophical grounding for deciding what kinds of knowledge are possible and how we can ensure that they are both adequate and legitimate. It is then the task of the researcher to identify, explain and justify the epistemological stance he/she adopted, (Crotty 1998: p8). Within objectivist epistemology researchers usually employ quantitative experimental analysis of data involving questionnaire survey. The social constructionist epistemology involves researchers employing a qualitative data with small numbers through face-to-face interviews with individuals or groups.

consciousness that can be measured and tested. The constructionist epistemology refutes the idea of objective truth and asserts that meaning (truth) is constructed not discovered, and that no meaning exists without a human mind. The third is subjectivist epistemology which holds the view that meaning (truth) is not constructed but imposed by human subjects on objects (meaning is seen as value laden – post modernist thinking which is close to subjectivist epistemology).

The social constructionist (conceptual lens in this research) assumption is interrelated to the narrative enquiry because, "the construction of stories occurs during the teller and listener exchange and when the teller is in the midst of the story he/she is telling.", (Good, 1994:p.153). The meaning construction from the stories engages the narrator and researcher in an active interchange and often co-constructed (Riessman, 1993; Clandinin & Connelly, 2000).

1.1.1.6   Key term: narrative in this research

Telling stories about personal experiences is a universal human activity and among the first forms of discourse that we learn as children (Nelson (1989) - in Riessman, 1993: p.3). As scholars point out, the *'Narrative Turn'*, (Riessman, 2008: p.14) or *'turn to narrative'*, (Denzin & Lincoln, 2000) marks differences in social science epistemological positions. The *'turn to narrative'* led to less researcher controlled practices and storytelling became material for close reading and analysis (Riessman, 2008: p.15). This is because in narrative[4] and story-telling, a speaker connects events into a sequence that is consequential for later action and for the meaning that the speaker wants the listeners to take away from the story, (Riessman, 2008: p.3). In this research then, story-telling engages the patient (story teller) and me (researcher) in story creation by organizing the order of events from the narrators' expressions through temporal sequence and progression that is called 'plot'. The story *'plot'* characterizes what the story-teller wants to convey to his/her listener (Emden, 1998; Riessman, 2008). Having discussed research problems, questions and the constructionist lens in this research, I will now explain the research context and key research terms.

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[4] **Narrative** may be used to mean anything beyond a bullet point and narrative forms are diverse in nature involving scientific research reports, biographies, diaries, archival documents, health records. Narrative as a form of human communication is also defined along the three ancient modes of discourses: poetic narrative (typically refers to literature, pure fiction); dialectic narrative (a form that represents fact empirically verifiable phenomena) and rhetorical narrative (by its nature sought to prepare the audience through the power of persuasion), (Lucaites & Condit, 1985: p93). Despite these apparent differences in narrative forms, all talks and texts cannot be narrative unless it captures the specific characteristics of sequential events in place and time, the meaningful human intention motives feelings action in representing the events. In this research, a more restrictive definition of narrative refers to a discrete unit of discourse, an extended answer by research participant to a single question, topically centered and temporally organized experience of events by each research participant, (Riessman, 2008).

1.2   Research Context: Tuberculosis illness and Pathways to medical care

The tubercle bacillus affects lungs *(pulmonary TB)* and many other bodily organs *(non-Pulmonary TB)*. Mycobacterium tuberculosis *(M.Tb)* is a bacterial infection transmitted through the respiratory system and lung is the first port of entry into the body. In a few hours after entering the lungs, the bacilli can escape into other organs and implant in areas of high partial pressure of oxygen, i.e. lungs; renal cortex and reticuloendothelial system (Palomino et al. 2007: p.489; Kumar and Clark, 1990: p. 678) for its survival. Approximately three to six weeks after infection with the disease, the body immune response to the bacteria occurs. This is an important stage for later detection of exposure to tubercle bacillus. The immune reaction occurs to TB bacilli that are present in sufficiently large numbers to trigger a body response called *'cell-mediated immune response'*. This process is what usually helps to detect TB infection using skin test called tuberculin skin test (TST) (Palomino et al. 2007; Kumar and Clark, 1990).

Figure 3 Tuberculosis *(M.Tb)* pathophysiology risk, infection, illness and healthcare pathways
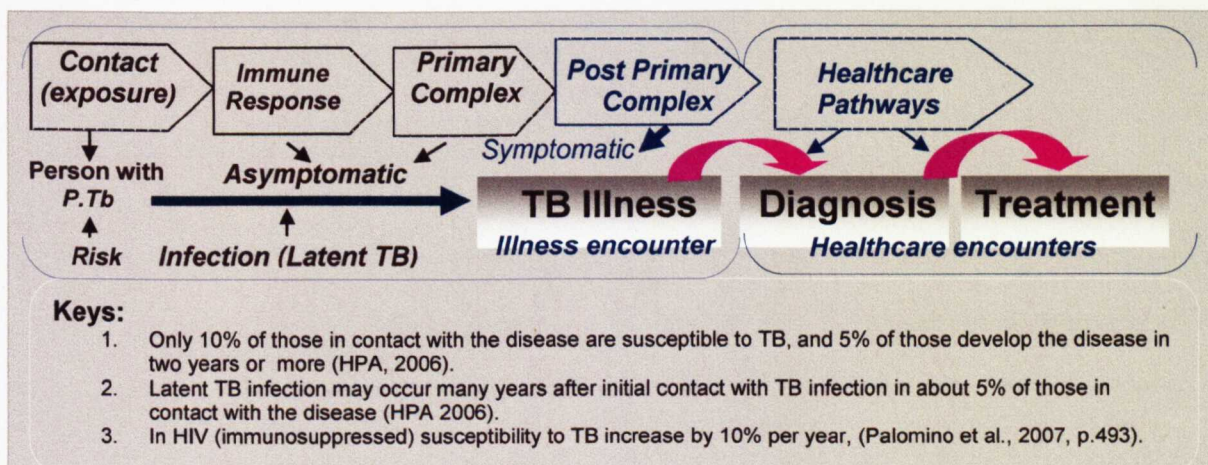
(Source: for contents: Kumar PJ, and Clark ML., 1990; Palomino et al. 2007)

The person with infection is usually asymptomatic and functions normally. As long as the immune system remains active, the bacilli stays in 'dormant' and resting stage is called the Primary Infection (Palomino et al. 2007: p.492; Kumar and Clark, 1990: p.679). Infection only leads to disease in a small proportion of subjects. Of those infected with TB, only 5% to 10% go on to develop the disease, (HPA 2006b:p.36) referred as post-primary complex. (Fig 3)

A number of factors have been associated with progress from infection to disease, for example, in those immunosupressed HIV co-infection with TB, leukaemia, and those who are malnourished, alcoholics and diabetics (Palomino et al. 2007: 492) and also homelessness, overcrowding, and poverty (Parry et al. 2004; Anderson et al. 2007). Late occurrence of the disease is called reactivation of latent TB, most commonly observed in the older generation of indigenous UK-born cases (Davies et al. 2002 – in Detels et al. 2002:p.1647). There is also a known latent form of TB observed in foreign-born subjects who

come from high TB prevalent settings, for example, African and south Asian ethnic populations in the UK (HPA, 2009). However, the recent HPA surveillance data indicates that in foreign-born cases nearly half of cases (45%) developed TB within five years of entry to UK (HPA, 2010: p.14). The duration of infection prior to entry to the UK is difficult to estimate and is not known.

The most frequent TB symptoms are: *lack of appetite, low-grade evening fevers and night sweats.* The respiratory signs are: insidious cough at any hour of the day, often starting with a dry cough and becoming productive (sometimes with blood), night sweat, chest pain, weight loss The non respiratory type of TB which has many forms involves almost any bodily organ: kidney; eye; skin; abdomen; bone; lymph glands; brain. Patients suffering from TB in any part of the body other than respiratory organ, usually experience some of the common symptoms as above; weight loss; fever; intense pain on affected site of infection; with localized swelling, (Palomino et al. 2007: p.494; NCCCC/RCP, 2006: p.32-6). Although these types of TB are non-infectious, the disease causes serious damage to the organ it affects. Severe complications involve brain damage in cases of TB meningitis, kidney failure; bone destruction, macular tissue degenerative changes and blindness if it involves eyes.

1.2.1 Key term: illness experience

A number of qualitative researchers have employed a narrative method in *understanding patients' illness experiences* using a case-centred approach. Michael Bury developed the concept of narrative reconstruction – his work demonstrated illness narrative as a means to understand the deeper meanings of patients' experiences (1982: p.179). His work was further applied by many other researchers. Williams (1984) in his research with rheumatoid patients found how illness as understood by professionals and by patients differed markedly. He notes that individuals' interpretations of the genesis of the same disease did not conform to the simple medical formulations of etiology of the doctors (in Riessman 2008: p.55; Pierret 2003: p.7). Furthermore, Arthur Kleinman 1988 refers to disease as the physician conceptualization of problem whereas illness is the subjective evaluation or response of a patient to his/her feeling unwell. It includes the experiences and also the meanings given to that experience, (cited in Jones 2009: p.13). Moreover, Kielmann (2005) states that within individuals' illness narratives (illness experience) many themes are covered including "perceived symptomatology, patterns of resort patients navigate through and the popular, folk and professional sectors of the medical systems in search of treatment and relief" (In Green & Browne 2005: p.138).

Much of the literature on TB suggests how TB is often misinterpreted, or perceived differently from one cultural/social group to another. In countries like the UK, the bigger issue is the perception that TB is a disease of the past, which necessitated to heightened

awareness of TB not only among the general public, but also in biomedical circles (DH, 2004: p.12). There is a general consensus that patients' perceptions, cultural beliefs and socio-economic situations play a strong part in the reasons for delaying care, (Palomino et al. 2007: p.494). In some situations, patients may also fail to understand TB symptoms. Since the publication of the *'Stopping TB in England'* there has been more emphasis on public education to raise awareness and tackle misconceptions about TB in the community (DH, 2004).

1.2.2 Pathways to TB diagnosis and treatment

A TB toolkit for commissioners - TB action Plan (DH, 2007a) states seven ways of contacts in patient's journeys from an initial contact to healthcare to the end of TB treatments. *(see Fig 4)* I have made an additional insertion to indicate *'cured'* and discharge of the patient in C8 and to incorporate the port-entry system in the pathway in C1 and C2. This is because the TB control programme, particularly in London, contains many routes to detect new cases of TB. First, the NHS primary care, mainly GPs, may detect TB cases through routine GP consultations. The port entry system is an active case finding method which was introduced in the 1960s and has been largely performed since the 1990s by port entry medical inspection teams (DH, 1992; HPA, 2006a). There is also in London a mobile chest radiography screening (active case finding) the DH pilot programme - has been operational in London since 2005, aimed at the homeless, new entrants and refugees (HPA, 2007a: p.26).

Figure 4   TB patients' pathways to TB diagnosis and treatment
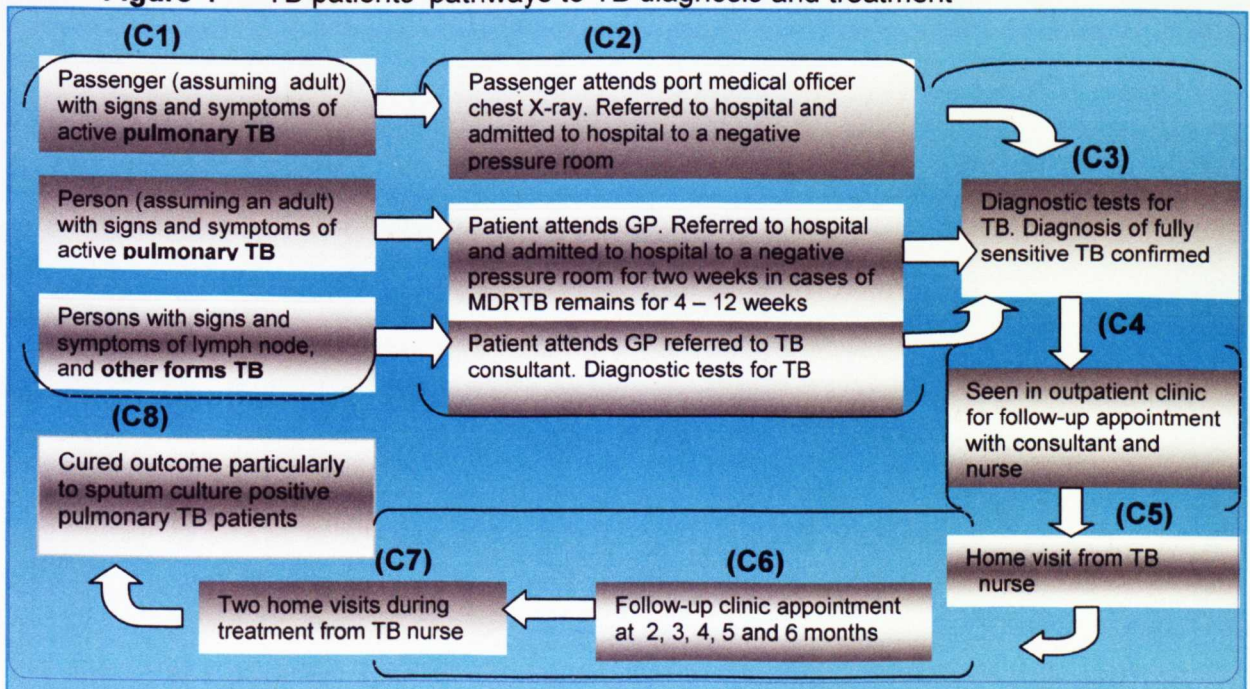
Source: (table contents): TB Action Plan Toolkit (DH 2007a)

In the UK, tuberculosis is a notifiable disease and it is a statutory duty of a doctor suspecting TB diagnosis initially to notify the Consultant for Communicable Disease Control (CCDC) by telephone (NCCCC/RCP, 2006: p.188). A standard notification form must follow promptly in all cases. The minimum dataset on each case currently includes notification details and demographic, clinical and microbiological information. Cases are reported by clinicians to local coordinators in the health protection unit (HPU), then via HPA regional units to the HPA Centre for Infections, Colindale (NCCCC/RCP, 2006: p.188).

Furthermore, the NICE guidelines also state that hospital chest departments and clinics are key service delivery units. There are four basic service models, the current model used in London is called: *Specialist hospital-based model:* TB nurses are based in chest clinics in local hospitals or specialist community screening units but have functions for the surrounding community (NCCCC-RCP, 2006: p.22). One exception is that in one of the research settings - St Thomas's Hospital TB nurses, the chest clinic is based in the hospital. The remaining two research sites, the Central Middlesex Hospital and the Newham University Teaching Hospital both have chest clinics in the community and the nurses are also based in these clinics.

The TB service care pathway (in Fig 4) is useful for background understanding of the context of patients' journeys through healthcare. From the perspectives of the patients' understanding, a pathway might include their own accounts of contacts, continuity of care between service departments/units, and the flow of information between health professionals and also with the patients. For patients with clinical symptoms suggestive of TB the journey could be streamlined, as shown above, to reduce the number of appointments a patient attends, as tuberculosis care pathways usually involve the medical practitioners' awareness and knowledge about TB. There are reasonable case scenarios contained in the Royal College of Physicians (RCP) and NICE guideline which set out to standardise medical doctors' practice in the UK (NCCCC/RCP, 2006). Initiatives to reduce TB transmission in the community "Stop TB partnership targets" and CMO's report state the need to detect 70% of cases with sputum smear-positive in the community and also to achieve 85% treatment completion rates (WHO, 2008; DH, 2004). The current London wide case detection rate may be difficult to measure with absolute certainty due to the lack of knowledge as regards how many there are with TB at any given point in time. However, in 2007 London achieved 84% treatment completion rates, the highest in the UK as a whole (HPA, 2010).

1.2.2.1 Key Term: TB diagnosis

Early diagnosis and starting TB treatment is a highly effective way of TB control to minimize complications, to cure individuals and prevent further transmission of TB in the community.

Untreated smear-positive 'open TB' case could infect more than ten contacts annually, (Styblo, 1991) and from 20 to 28 susceptible individuals during the illness (Jochem K et al. 1999 in Porter et al. 1999: p.34). A minimum two weeks continuous treatment has significant benefits in reducing the chance of transmission from person to person (NICE, 2006).

Diagnosis can be the most intellectually challenging aspect of medical reasoning, where the doctor encounters: the patient with illness history (story telling) and medical problem, and other information involving the patient (prior risk from history) (Dowie and Elstein, 1988:p.245). Doctor-patient communication (medical encounter)[5] involving TB is where the clinical judgment on the part of the doctor is expected to follow a standard procedure: clinical history; physical examinations; referral to diagnostic centres and notification of suspected TB diagnosis. The ability to draw from a range of probabilities that the patient's medical problem is the disease "A" rather than the disease "B" is dependent on many factors. Several factors have been known to affect the doctor's ability to process patients' information: the circumstances surrounding information exchange between the patient and the doctor, amount of time available for consultation, the doctor's style of consultation, (Morgan, 2003: p.56) In most situations, clinicians also use the pattern of specific health problems that give rise to concern in population (Dowie & Elstein, 1988).

Figure 5 Major types of GPs' decisions network of a particular health problem
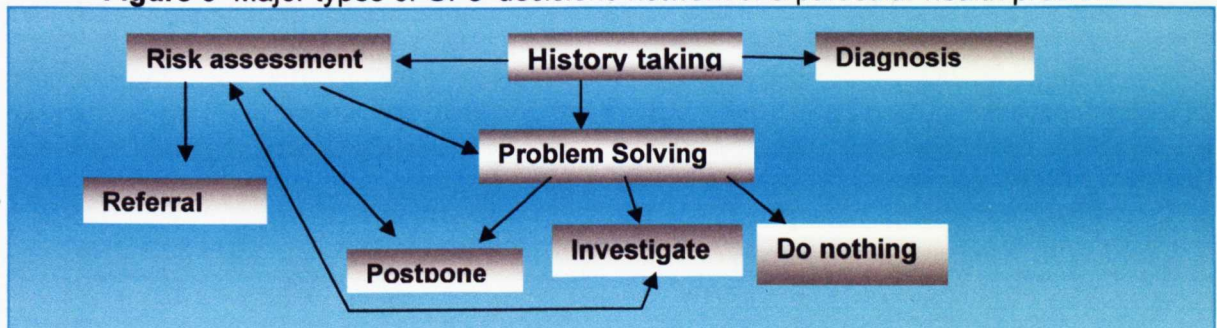
(Source: Dowie and Elstein 1988, **p.**248)

Dowie and Elstein (1988) represent a cognitive map of the major classes of GP decisions as a network of rules, as Fig 5 above illustrates. The condition under which a particular decision is made can be described by network of *'meta-rules'*. A doctor listens to a patient's 'illness story' (history taking), and makes a diagnosis based on the patient's history of illness. The doctor undertakes an *'assessment of risk'* and decides to refer a patient.

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[5] **Medical encounter** or doctor-patient communication is a type of relationship which largely occur when a patient seeking medical help from the doctor. A patient with a health problem or concern sees a doctor for medical help. The medical encounter is achieved in a problem-oriented interaction. The patient with a problem telling the doctor about his problems and a doctor by his professional expertise and knowledge listen to a patient history of the problem and ask specific questions to understand the point-of-view of the patient (*subjective data*). The physical examination, risk assessment, specific tests and any other previous tests or history (*objective data*) help a doctor form clinical decisions including most probable diagnosis and necessary course of action to resolve the problem presented to him by the patient, (Morgan 2003; Légaré et al. 2007).

Based on the patient's history in order to solve problems he/she may also decide to: (1) undertake a 'specific investigation'; (2) *postpone* as I understand it perhaps with an offer of symptomatic treatment; or (3) 'do nothing'. (see Fig 5) The clinical literature description of the processes of TB diagnosis involves different test procedures and techniques depending on the type of mycobacterium and the site of the disease. Table 1 below provides current specific tests 2 - 9 used either to suggest or detect TB infection or disease. These test procedures and facilities are only available within the diagnostic centres largely found in hospital settings.

Table 1   Major types of TB diagnostic tests

Types of diagnostic tests	Purpose to detect		Requirements for	
	Illness	Infection	Time	Accuracy
1. **Clinical History:** signs and symptoms; physical examinations	Yes Suspect TB	No	In an hour	Clinician's knowledge, skills and doctor – patient communication style.
2. **Radiography – X-rays:** *chest, or site of infection*	Yes	No	Minutes	Severity of lobar infiltrates and cavitations of lungs
3. **TST (Tuberculin Skin Test)**	No	Yes Screening	2 - 3 days	Test administration & techniques. Unreliable in BCG vaccination and HIV infection.
4. **Microscopy smear examination:** *sputum, fluids, biopsy, urine etc.*	Yes	No	2 hours	Quality of specimens and test processing
5. **Fluoroscope**	Yes	No	1 day	More accurate than ordinary microscopy
6. **Culture examination** *sputum, fluids, biopsy, urine etc.*	Yes	No	2 to 6 weeks	Gold standard for active TB
7. **NAAT** *(nucleic acid amplification techniques)*	Yes	No	1 day	Reliable and higher diagnostic accuracy
8. **IGRA** (Interferon-y release assays) T-SPOT.TB and QFTG/G-IT	Yes	Yes	1-2 days	High sensitivity and specificity for M.Tb cells and LTBI
9. **Computed tomography**	Yes	No	In an hour	False positive in non tubercular mycobacterium

Sources: Lange & Mori, (2010); Detels et al. (2002:p.1643-57); Palomino et al. (2007) and Knechel (2009)

A key insight into this in the context of medical help involves telling by a patient and listening by a doctor. The need for interpretation of sign and symptoms is one aspect that requires the skill of a doctor, prior knowledge of TB and an understanding of the patient's mode of explanation about his/her illness in the consultation room, Kleinman, 1988 - (cited in Green & Browne, 2005:p.138). Pioneer anthropologist Cheryl Mattingly (1994) describes the doctor's reinterpretation of the patient's illness story as *'clinical emplotment'*, referring to the many factors likely to hinder a doctor's *clinical-history* taking and interpretation of patient's perspectives. The potential for negotiation, mutuality of shared understanding between health workers and their patients may also be complicated by patients' level of understanding and available time with the patient (Morgan, 2003: p.56/7).

In the UK, the CMO's proposal of a five-yearly revalidation of doctors' medical licenses through feedback from patients, new skills learned, and patient complaints' put more emphasis on the communication skills of doctors with their patients, (Boseley, 2008). This may relate to existing macro-level regulatory mechanisms that seek to change doctors' practice to reflect a patient-centred care NICE recommends. In terms of TB, delaying

diagnosis due to low index suspicion of TB by clinicians is also linked to the knowledge and skills of the doctor. (see Tab1 point 1) However, the DH & NICE published evidence-based (EB) clinical standards with clinical indicators and algorithms to standardise TB risk assessment from the signs and symptoms (NCCCC/RCP, 2006: p.33) the patient tells his/her doctor (history taking).

1.2.2.2 Key Term: TB treatment

The treatment process of tuberculosis is the most challenging for the patient where treatment encounters involve taking several drugs classified as first–line and may also involve treatment with second-line drugs, e.g. in cases of treatment failures. The first-line drugs for active TB called *'the six-month four drug regimen'* involves: six months isoniazid (INH), and rifampicine (RIF) supplemented in the first two months with pyrazinamide (PZA) and ethambutol (EMB)'. (NICE, 2006: p.4) In patients with active meningeal TB a treatment regimen is lasting for twelve months, comprising the four drugs: INH; RIF; PZA; RIF for two months followed by isoniazid and rifampicin for the remaining period (NICE, 2006: p.4).

Each drug from these combinations has a particular effect on tubercle bacilli. For example, isoniazid acts on highly dividing bacilli, ethambutol suppresses its replication, pyrazinamide and rifampicin has sterilizing capacity (Parry et al. 2004). This treatment regimen is considered as a *'gold standard'* with better TB cure and completion rate >95% and only 0-3% relapse rate' (NCCC-RCP 2006:p.59). The risk of TB infectivity can be minimized after two weeks of treatment and a patient may become smear negative after two months of initial phase treatment, (Parry et al. 2004: p.338) meaning no active bacilli may be found on repeat sputum smear test. Almost all these treatments have unpleasant side effects for the patients. Amongst some unpleasant experiences of first line TB drugs[6], rifampicin may turn urine orange; patient should not be taking any alcohol; pyrazinamide may cause a hypersensitivity reaction (Laloo et al. 2006 – cited in Neil, 2008: p.948) and gout due to hyperuricaemia (Palomino et al. 2007: p.606). Although, amongst the first-line

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[6] **Side-effects: Isoniazid (INH)** has some neurological or hematological adverse effects and hypersensitivity reactions occur less frequently. A daily dose of 10 mg of pyridoxine hydrochloride is recommended to reduce neurotoxicity and to treat adverse effects caused by INH. Rifampicin (Rifampin – **(RIF)** adverse effects in the gastrointestinal tract, skin, kidney and nervous system, and thrombocytopenia (tendency to bleed easily on the skin), a red-orange coloration of body fluids such as urine, tears, saliva, sweat, sputum and feaces. **Pyrazinamide (PYR)** can cause hyperuricemia (loss of calcium), leading to attacks of gout. **Etahmbutol (EMB)** usually affects visual acuity, constriction of visual field, some form of colour blindness one or both eyes. (*Fraunfelder 2006:. - in Palomino et al 2007, p.606)* **Streptomycin (SM)** has ototoxic effects affecting vestibular rather than auditory function, which manifest as dizziness and may produce renal failure when administered with other nephrotoxic agents. Regular assessment of both auditory and renal function is recommended. In case of severe adverse effects, SM can be removed by hemodialysis, (Palomino et al. 2007: p.593-634).

medications isoniazid and rifampicin are important, outbreak of resistance to isoniazid is becoming one of the main concerns in London. The outbreak of resistance is particularly seen in UK-born (53%), compared with non UK-born (37%) and most non-UK-born cases are from Ireland, Jamaica and Somalia (HPA, 2007a: p.20). There have been 134 cases of isoniazid resistant and nineteen cases of multi-drug resistant cases in London, (HPA 2009: p.23) nearly half of all cases in England as a whole.

According to the NICE guidelines, the duration of treatment is varied and dependent on the type of drug and the pathogen forming resistance. Among non-MDR TB forms, isolated resistance to ethambutol is uncommon and requires six months of treatment, whereas isolated resistance to pyrazinamide requires nine months of treatment. A longer period of treatment of 18 months, however, is needed for cases with combined streptomycin and isoniazid resistance or isolated rifampicin resistance, (NCCCC/RCP, 2006:p.102–3). The WHO recommendations for MDR treatment are, however, for a minimum of 18 months with an extension of the therapy to 24 months in cases with extensive pulmonary damage (WHO, 2010b:p.91).

However, in a cohort study in London researchers found extended treatment was associated in those with alcohol or drug use; previous TB treatment and patients and anticipated difficulty taking their medications, (Craig et al. 2007b). The patients' treatment adherence is crucial in TB control. The NICE guidance provides risk categories for planning directly observed treatment (DOT) and social support to mitigate factors may reduce treatment adherence (NCCCC/RCP, 2006:p.83). However, this study is not designed to investigate the patients' experiences of social care and support provided by community agencies during treatment. The study sought to learn about patients' experiences of medical help from professionals. This is based on the ethics committee guidance requirements and will be discussed more in Chapter 3.

1.3   Summary of the Chapter

In this Chapter, I presented, discussed key historical and political, policy contexts and how they relate to the threats of TB in London. The problem statement highlighted the knowledge gaps in relation to barriers to diagnosis and treatment related either to the patients or providers of care. The purpose of this study is to contribute to this gap in knowledge from patients' stories of their experiences of events leading to diagnosis and treatment. The research questions, its conceptual lens for narrative enquiry and the key research terms have been discussed.   The inclusion of key research terms and research contexts was intended for readers to gain a contextual understanding of medical help: from first contact to healthcare, diagnosis leading to TB treatment (the parameters of this research). I used these research contexts and concepts as schemes of references (second order constructs)[7] that make sense to me in the discussion of participants' experiences of medical help. My approach in this research was to understand research participants' experiences of events in their medical help by being reflexive[8] meaning focused on the event as it was experienced, reflected on, described and interpreted by participants based on their perspectives or views (fist order constructs)[9].

Chapter 2 will look at the review of literature and discuss its main limitations in relation to patients' experiences of pathways to TB diagnosis and treatment and highlight how the thesis questions remain under research.

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[7] **Second order constructs:** are constructs the researcher employs schemes of reference that make sense to him and may draw from relevant theory or policy literature in his professional purview. These constructs should be understandable by the scientific community where the researcher comes from (Schutz, 1962: p.59).
[8] **Reflexive:** also referred as interpretive to emphasize the production of meaning from the perspectives of research subjects rather than the conceptualizations from theories (Denzin and Lincln 2000: p.445-50). Being reflexive in the interpretation of meaning from narrative teases out what is said the content and how something is said in the context.
[9] **First order constructs:** are the constructs that help to understand the social actor level of meaning reflect the type of subjective evaluation, interpretation they use (Schutz, 1962: p.59).

Chapter Two: Pathways to TB diagnosis and Treatment: Narrative Review of Scholarly Literature

2. Introduction

This chapter will begin with a background to the review in to master narratives[10] that shaped current knowledge of factors that are known to influence patients' pathways to diagnosis and treatment. The strategy employed for literature search, the review method and results are provided. In discussion, a critical review of published studies, the gaps and limitations of literature are provided. The case for a narrative enquiry approach and summary of the research problems and topics that remain under research are also presented.

2.1   Background of Review

The review of literature on patients' pathways to diagnosis and treatment, the *dominant stories (master narratives)* make particular reference to the social, economical, physical and cultural influences on TB patients and their families' healthcare access. More specifically, these master narratives often portray factors associated with delaying diagnosis and treatment either by linking it to the patient or to the provider of TB services.

In these portrayals, on the one hand, TB patients are embodiments of wider influences of poverty; lack of knowledge about TB; misconceptions due to cultural beliefs; and social stigma. Their ability to seek health care is often understood to be influenced by these and many other factors. On the other hand, the storyline, or *master-narrative*, also depicts that the health care provider and system-related factor was in part responsible for delaying diagnosis and treatment for patients. Literature often made reference to providers' sub-optimal care and failure to diagnose early and initiate treatment after the patient seeking medical care. This has been referred to as low suspicion of TB (a concept) often associated with the skills and knowledge of a doctor who provides medical help for a patient (Palomino et al. 2007: p.494; Rao et al. 1999).

In assessment of pathways to TB diagnosis and treatment time length measurement have been used in literature. The storyline defines 'patient-delay' as an 'indicator' the time

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[10] **Master narrative** is sometimes defined 'as the big story, the highly articulated world view, ideology...', (Denzin & Lincoln 2000: p.303). "A master narrative also called grand narrative or meta-narrative is a web of meanings that reflects cultural themes and beliefs that give a local story its coherence and legitimacy that we find convincing and persuasive. Our adherence to a master narrative dictates how we frame stories, whom we interview, the questions we ask and ultimately the work we produce, which typically reinforces our belief in the master narrative" (Zilber et al. 2008). Zilber et al note that meta-narratives are not consciously acknowledged by the teller but shape the construction of the story and shape the 'plot' to be extricated bottom up through interpretive moves discovering the meaning systems that gives sense to the story. What we know or believe makes the story sound plausible to us, (2008:p.1054).

from initial TB symptom manifestation to first contact with health care by a patient. In reviewed literature, delay over 60 days by the patient constitutes 'patient-delay' (Storla et al. 2008). Literature also defines 'provider-delay' as the time from first contact by the patient to starting TB treatment. In the measurement of this indicator an acceptable time period to constitute the provider delay; a cut off point of over 30 days was used' (Storla et al. 2008).

The purpose of this review is to understand from literature how research approached to investigate barriers and facilitators, with a purpose to critically review the research approach and highlight gaps the review has identified.

2.1.1   The Search strategy

The initial phase of the review included electronic searches using key search terms to look for relevant literature on Cochrane Library, MEDLINE (from 1950 to May week 4 2011), EMBASE (from 1996 to 2011 week 4) and Pubmed. A total of 90 studies from EMBASE, 520 studies were cited on MEDLINE, 225 studies from PubMed and 195 citations from Cochrane met search terms. At the title stage 950 studies and 20 studies at the abstract review were excluded as they did not meet the inclusion criteria. The full texts of seventy studies were included for full review. (see Annex 5, p.255-63) In addition, bibliographical reference search on Google, library archived journals identified 16 qualitative studies and three studies recommended by others were also included for full-text review. (see Fig 6 below) The full texts of 89 studies were screened for relevance, of these 67 studies were selected for the purpose of this review (selected studies are listed in Table 2a and 2b).

2.1.1.1   Purpose of Review and Search Criteria

The purpose of the review was to identify as much as possible the literature concerned with pathways to TB diagnosis and treatment in order to assess their relevance to patients' experiences. In assessment of relevance of literature, the focus of the study (its aim), sources of data method (the processes) and its findings (claims that are made) were used. The following criteria were employed for selecting studies for the review
Inclusion criteria:

- Types of studies: All published studies investigating patients' pathways to TB diagnosis and treatment. Patients' pathways may involve their journey from TB illness to diagnosis and treatment services.
- Research participants: studies involving TB patients (over the age of 15 years) or TB service providers in high, medium and low TB prevalent countries
- Research settings: primary care, private doctor or acute hospital medical care.
- Research outcome measures: factors known to influence early diagnosis and treatment

Figure 6   Flow diagram of study selection process

Search Citations Identified Studies

Citations identified through electronic search   (n= 1030)

Studies excluded at the title review (n = 950)

Included for abstracts review (n = 90)

Included for full-text review (n = 89)

Studies reviewed   (n= 67)

Expanded search
Included full-text studies
(n= 19)

MedLine   (A) = 520
PubMed   (B) = 225
Embase   (C) =   90
COCHRANE (D) = 195

Abstracts selected for
Full-text review
A = 7.   B = 56.   C = 7

Abstract included for full text
review   (n=70)
Full articles included from
expanded search (n=19)

Excluded including duplicates

A = 513
B = 168
C = 81
D = 195

Excluded at abstract
review   (n=20)

Excluded at Full text
review (n=22). (see
Annex 5 p.252-4
reasons for
exclusion

A list of UK studies
excluded and
reasons has been
provided in Annex 5
p.253-4.

Reference
Google web   = (n=16)
Library catalogue
Recommended by   =   (n = 3)
others
Total   =   19

2.1.1.2   The Review Method and rationales

The review included studies from several countries with differing contexts of socio-economic and cultural backgrounds. In tables 2a and 2b, I have grouped studies from the Organization for Economic Cooperation and Development (OECD) and 'non-OECD' countries literature thematically using key markers. (see Annex 5, p.262-71) In synthesizing data from each paper, relevant information was noted down using specific markers for the purpose of the review.

The method employed is a narrative review of literature rather than a systematic review. A narrative review of synthesizing literature is descriptive rather than systematic. The systematic review often involves a comprehensive appraisal of literature and quality assessment criteria recommended for qualitative studies by Popay et al. (1998); Mays and Pope (1996) and BSA medical sociological Group, 1996 – (cited in Khan et al. 2001: section 2.5.8 p.13-40). Assessment criteria recommended for quantitative studies by Khan et al. (2001: phase 5, section 2.5.3, p. 4-5).

In narrative synthesis of literature, this review has focused on the following key markers of study's: 1). aim(s). 2). method(s). 3). data sources for analysis. 4). key finding(s) (knowledge). 5). relevance of findings to patients' experiences. Grouping literature thematically helps to review both quantitative and qualitative literature, reveal differences, commonalities and gaps where little research has been undertaken.

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i.   Rationales for Method of Review

To begin with, the interconnectivity of our globalized world is a rationale for assuming that the socio-cultural and bio-medical practices involving TB define the scope of this review as more global than local. This is because tuberculosis is a disease often associated with poverty (Bhatti et al. 1995) and lack of access to medical care that have been a common feature of literature in the context of developing southern settings and also industrial northern settings. The global focus is important not only to appreciate the commonalities and differences but also gain insights into weaknesses and strengths in a more comparable way, e.g. grouping literature from countries of OECD (a mandate that covers economic, environmental, and social issues) and literature from countries of non-OECD (mainly known to be less affluent groups).

Secondly, the rationale for employing narrative descriptive review is also that the systematic review of evidence for generalization is inapplicable for this review. As noted in chapter 1, the thesis social constructionist lens recognizes reality has many forms and relative to time and contexts that are changing. As stated above, the review purpose is to understand from literature how research has approached to the investigation of factors determining patients' pathways to diagnosis and treatment. In my view this is more applicable to a narrative review rather than applying a comprehensive systematic evidence synthesis.

2.2 Results of Review

Of a total of sixty-seven studies were identified for the review, twenty-two studies applied cross sectional (CSS) either survey or interview and only three in OECD settings (in Table 2b) reported measuring outcomes using a questionnaire. Fifteen studies examined clinical records and surveillance data (MR&SD) and only four in non-OECD settings (in Table 2a). Twenty-five studies applied qualitative research. Nine studies applied semi structured interviews (SSI) and six studies structured interviews using questionnaire interviews (SQI) (see Table 2a and 2b). Six studies applied In-depth interviews (Ind.Int.) and four applied focus groups (FG) interviews (see Table 2a and 2b). Three studies selected for the review were systematic reviews of literature (Srev). A further two studies employed: a cohort study (Coh. std), and a nested case control study (Nca/co std). Study populations were described as *'newly diagnosed', 'smear + cases', 'adults with cough' 'hospitalized patients'* or *'symptomatic TB patients'* have been used in literature. (see Table 2a and Table 2b)

2.2.1 Help-seeking and Healthcare Seeking Overview of Literature

In a broad overview of literature, the sources of dominant thinking determining healthcare utilization by patients was understood to involve individuals' (patients') perspective of illness experience (behavioural intention) on one end of the continuum and individuals' (patients') experiences of their healthcare on the other end of the continuum.

The patients' behavioural perspectives, help-seeking (illness behaviour) - refers to a phenomenon often used to describe 'what people do when they are ill' (Green and Browne. 2005) and 'the way a person behaves when he/she feels a need to act' (Eloy et al. 2004). In these depictions, patient's decision to seek healthcare may be shaped by their own experiences, beliefs system, (Becker, 1974) and values "lay theories, lay perspectives" (Armstrong, 1994; Hyden, 1997) socio-cultural, socio-economic, knowledge, attitudes, personal skills (Tone and Green, 2005).

Patients' (users') experiences of healthcare related to 'healthcare seeking', which refers to a phenomenon 'the end stage in the continuum of the patients' experiences of medical help from professional', (Muela-HS, 2003). At the macro level, healthcare policy exhibits a number of factors that are seen to influence patients' experiences of provider's care. These factors include service, accessibility, timeliness, quality, safety, effectiveness, dignity, respect, and sensitivity to patients' needs (DH, 2007b). Within these factors, providers' care should be patient-centred (NICE, 2006), and TB service, design, and care delivery should be informed by patients' experiences (DH, 2004).

The review of selected studies presented in Annex 5 p.255-63 Table 1 and Table 2 will highlight themes from researchers' aims, research outcome measurements (key data sources / types) used and key findings they have presented in their literature.

Table 2a Literature from non-OECD Countries (Full Review in p.262-7)

Authors	Settings/Country	Method	Patient delay	Provider Delay
1. Thorson et al. 2000	HA Tay - Vietnam	CSS		
2. Grover et al 2006	Rural/Urban - India	CSS	√	
3. Demissie et al. (2002)	Addis Ababa - Ethiopia	CSS	√	
4. Kiwuwa et al. (2005)	Kampala - Uganda	CSS	√	
5. Ahsan et al. (2004)	Rural Bangladesh	CSS	√	√
6. Togby et al. (2006)	East Sikkim- India	CSS	√	√
7. Sadiq et al. (2001)	Rawlpindi - Pakistan	CSS		√
8. Godfrey-Faussett et al (2002)	Lusaka - Zambia	CSS	√	√
9. Van der Werf et al. (2006)	Kiev City - Ukraine	Quali , MR	√	√
10. Peheme et al. (2007)	Countries, Estonia	Quali		√
11. Auer et al. (2000)	Manila - Philippines	SSIs	√	√
12. Sudha et al. (2003)	Tamil Nadu - India	Quali	√	
13. Enwuru et al. (2002)	Lagos - Nigeria	CSS	√	√
14. Huong et al. (2007)	Rural - Vietnam	CSS	√	
15. Yimer et al. (2005)	Regional – Ethiopia	SQI		√
16. Ngamvithayapong et al. (2001)	Chang Rai- Thailand	Quali	√	√
17. Lienhardt. (2001)	Rural/Urban - Gambia	Quali		√
18. Salaniponi et al. (2000)	Rural - Malawi	CSS	√	
19. Rajeswari et al. (2002)	India	Quali	√	
20. Maamary (2008)	Syria	CSS	√	√
21. Pronyk et al. (2001)	South Africa	CSS	√	√
22. Odusanya et al. (2004)	Lagos Nigeria	CSS	√	
23. Dos Santos et al. (2005)	Recife - Brazil	Quali	√	
24. Harper et al. (2003)	Gambia	Quali	√	√
25. Macq et al. (2004)	Nicaragua	CSS		√
26. Aye et al. (2010)	Districts - Tadjikistan	CSS	√	√
27. Meinntjes et al. (2008)	Cape Town	Quali & MR	√	√
28. Hui-Ping et al. (2009)	Taiwan	SD	√	√
29. Lawn et al. (1998)	Region Ghana	QS & MR	√	
30. Faziul Karim et al. (2007)	Bangladesh	CSS	√	
31. Liefooghe et al. (1997)	Kenya	FG	√	√
32. Eastwood & Hill (2004)	Gambia	Quali	√	√
33. Edington et al. (2002)	Tintswalo SA	Quali	√	√
34. Johansson et al. (2000)	Vietnam	FG	√	√
35. Npang et al. (2007)	Rwanda	FG	√	√
36. Asbroek et al. (2008)	Nepal	interviews,	√	√
37. Squire et al. (2005)	Malawi	Quali	√	√
38. Watkins et al. (2004)	Bali - Indonesia	Quali	√	√
39. Needham et al. (2001)	Lusaka - Zambia	Quali	√	√
40. Gelaw et al. (2001)	Addis Ababa - Ethiopia	CSS		

Table 2b Literature from OECD Countries (Full Review in p.68-71)

Authors	Settings/Country	Method	Patient delay	Provider delay
1. Calder et al. (2000)	Auckland	Survey	√	√
2. Samiento et al. (2006)	New York	CSS	√	√
3. Farah et al. (2006)	Norway	MR	√	√
4. Ward et al. (2001)	Queens Land - Au	MR	√	√
5. Sherman et al. (1999)	New York - USA	MR	√	√
6. Moudgil et al. (1994)	Lothian Scot UK	MR	√	√
7. Lewis et al (2003)	London UK	MR		√
8. Rodger et al. (2003)	London	SD	√	√
9. Gibson et al. 2005	Canada	FG	√	√
10. Nnoaham et al. (2006)	London – UK	Quali		
11. Leung et al. (2007)	Hong Kong	CSS	√	
12. Paynter et al. (2004)	London - UK	SD	√	
13. Storla et al. (2008)	System. Review	Srev	√	
14. Sagbakken et al. (2010)	Oslo - Norway	Quali		
15. Marais (2007)	London - UK	Quali		
16. Metcalf et al. (2007)	SE Wales – UK	Quali		
17. Okur et al. (2006)	Istanbul- Turkey	Quali		
18. Gershon et al. (2008)	Ontario - Canada	SD	√	
19. Cummings et al. (1998)	California - USA	Coh std		
20. Goulb et al. (2005)	Maryland - USA	Nca/co		
21. HO- M-J et al. (2004)	New York - USA	Quali		
22. Diez et al. (2005)	Regions Spain	MR	√	
23. Gagliotti et al. (2006)	Emilia region Italy	SD	√	
24. Sreeramareddy et al. (2009)	Systematic Rev	SRev	√	
25. Smith et al (2006)	London - UK	MR		
26. Waisbord (2004)	Lit. Reviews	SRev	√	
27. Gerrish et al. (2010)	Sheffield – UK	SSI	√	

Keys:

CSS	=	Cross Sectional Study
FG	=	Focus Group
SD	=	Surveillance Data
MR	=	Medical Records
SSI	=	Semi Structured Interviews
SQ	=	Structured Questionnaire
Quali	=	Qualitative (SSI, II, FG, SQI)
Ind Int.	=	In depth Interview
Coh std	=	Cohort Study
N Ca/Co	=	Nested case control
Srev	=	Systematic Reviews

2.2.1.1   Key marker 1: What was the research aiming to investigate?

The review highlights key themes from what the researchers' were aiming to investigate in order to understand barriers to TB diagnosis. These factors that the researchers have looked into in their investigation contain nine main areas listed as below.

- patient's beliefs, perceptions, attitudes and diagnostic delay.
- patient's experiences and behaviour, practices and delay.
- gender differences in healthcare seeking behaviour.
- socio-cultural factors and non biological influences of diagnostic delay
- risk factors and determinants of diagnostic delay (length of time).
- pathways to diagnosis and treatment.
- provider and patient diagnostic delay.
- healthcare diagnostic delay, (frequency of healthcare contacts, length of unspecific treatment and test provisions).
- health system delay and costs to the patient.

2.2.1.2 Key marker 2: How was the data gathered and analyzed?

The review highlighted diversity of data collection techniques and data types employed by researchers in their topic of investigation. Six markers of main data collection techniques and also type of data gathered by researchers' are listed as below.

- Patients' response to face-to-face and self completed questionnaire (survey).
- Patients' retrospective accounts of events to diagnosis and treatment (interviews).
- Views of others: careers, community members and professionals (interviews)
- Healthcare contact data from surveillance datasets or clinical notes.
- Clinical notes in combination with patients questionnaire survey.
- Surveillance datasets and questionnaire survey with professionals.

2.2.1.3 Key marker 3: What are the main findings on the topic?

The narrative review of studies has found several barriers/determinants of patients' ability to seek healthcare and providers' ability to diagnose and start TB treatment. The section below will present themes from researchers' findings. First, themes from study's findings related to the patients are grouped. In second, then themes from findings related to the providers of care are also summarized.

A. Patient-related barriers

Studies that reported barriers associated with the patients' determining pathways to early diagnosis and treatment are grouped into four main categories of factors: *Biological and pathological; Psychological and Socio-cultural; Personal choice preference and education; Poverty and socio-economic factors.* Study authors indicated in bold are UK-based studies.

*i. **Biological and pathological factors:** age, sex, ethnicity and severity of illness*

Eight studies have found that being female is associated with a risk of delaying care, (Thorson et al. 2000; Liefooghe et al. 1997, Ahsan et al. 2004, Needham et al. 2002; Fazlul et al. 2007, Ngmvithayapong et al. 2001; Huong et al. 2007, Rodger et al. 2003; Harper et al. 2003). Four studies were cross sectional looked into health seeking behaviour and gender differences using demographical, healthcare contact data for statistical analysis. Three studies interviewed patients but also gathered gender and socio-demographical variables for data analysis. The remaining one study used surveillance data to generate similar sets of findings.

Six studies also found that being elderly (Fazlul et al. 2007; Hui- Ping et al. 2009, Farah et al. 2006, Sherman et al. 1999, Ward et al. 2001) and Storla et al's 2008 review of studies. However, others documented no association with gender, (Kiwuwa et al. 2005; Rajeswari et al. 2002) or old age (Demissie et al. 2002). Studies found being elderly as a risk factor examined records and demographical data, i.e. age in their analysis. Interestingly, the three studies reported no association with age have used cross sectional survey with patients rather than using records to identify different sets of results and concluded differently.

Being part of particular ethnic group is also associated with risk of delaying care, in four studies (Hui-Ping et al. 2009, Huong et al. 2007, Rodger et al. 2003, Gibson et al. 2005) and two studies found migrants status, (Ward et al. 2001, Gibson et al 2005) one documented that born in high-prevalent setting, (Paynter et al. 2004) as risk factors of delay. Four studies gathered surveillance data and applied record analysis. All four studies based their findings on analysis of ethnic differences. Interestingly Gibson et al's study applied group interviews but their findings focused on ethnic differences and migrant status rather than experiences of participants they had interviewed.

In regard to disease pathological factors studies found that patients with non-pulmonary type of TB delaying medical help, (Farah et al. 2006, Moudgali et al. 1994; Lewis et al. 2003). All these studies concluded that non-pulmonary patients experience increased diagnostic delay and their findings are based on analysis of clinical records.

Four studies found duration of illness and severity of symptoms experienced by the patients also have been associated with increased diagnostic delay, (Leung et al. 2007; Dos Santos et al. 2005, Asbroek et al. 2008 and Storla et al's review 2008). These studies examined factors from the patients' experiences of symptoms severity and risk to delaying their diagnosis. Interestingly, Asbroek et al's study looked into patients' pathways and interviewed patients to discover how they first perceived their symptoms and navigate

through the healthcare system. They concluded that the severity of symptoms in part a risk factor of delaying diagnosis.

ii. Psychological and socio-cultural: knowledge; perception; belief and stigma:

Seven studies have found healthcare seeking behaviour for TB is influenced by a patient's knowledge of TB symptoms, (Enwuru et al. 2002; Liefooghe et al. 1997; Eastwood et al. 2004; Rajeswari et al. 2002; Salaniponi et al. 2000; Johansson et al 2000; Demissie et al. 2002), while others found low perception and lack of awareness of the severity of symptoms, (Sudha et al. 2003; Salaniponi et al. 2000; Harper et al. 2003). Amongst studies documenting positive association, five studies gathered socio-demographic, patients' knowledge of TB symptoms and educational level data for analysis and generate their findings. The remaining two studies found belief in familial inheritance and poor knowledge of TB through interview with the patients.

Seven studies found a perception that the symptom is not serious enough to seek help, (Calder et al. 2000; Van der Werf et al. 2006; Sarmiento et al. 2006; Nnoaham et al. 2006; Eastwood and Hill. 2004) or a perception that symptoms are associated with smoking, (Kiwuwa et al. 2005) or asthma, (Liefooghe et al. 1997) have also had an influence. All but two studies applied statistical analysis using a wide range of data collection methods and assessed patient delay from the debut of any TB symptom. The remaining three studies gathered subjective data through interviews with patients to conclude that patient' perceptions and judgements increases risk of delay from seeking help.

Moreover, it has been documented that delaying medical help is also associated with personal belief, (Auer et al. 2000; Edington et al. 2002) and the impact of social stigma, (Auer et al. 2000; Liefooghe et al. 1997; Eastwood et al. 2004; Edington et al. 2002; Johansson et al. 2000; Squire et al. 2005; Gelaw et al. 2001; Nnoaham et al. 2006; Maamary, 2008). Six studies gathered subjective data for analysis in order to generate their findings. The remaining two cross sectional studies gathered socio demographical data and healthcare contacts using questionnaire and group interviews for statistical analysis.

iii. Choice preference and education: self treatment, use of traditional healers, literacy

Patients' multiple contacts with different providers before diagnosis to be a risk factor to diagnostic delay, (Npang et al. 2007; Storla et al's review 2008 & Yimer et al's study 2005). Several studies have documented that help-seeking from alternative sources, i.e. private healthcare and traditional healers delay seeking healthcare (Needham et al. 2001; Thorson

et al. 2000; Eastwood et al. 2004; Liefooghe et al. 1997; Pronyk et al. 2001; Maamary et al., 2008; Yimer et al. 2005; Ho-M-J et al. 2004; Harper et al. 2003; Npang et al. 2007; Yimer et al. 2005).

A wide range of methods and data collection techniques were applied by studies in this category and only two were from OECD countries. Six studies applied qualitative narrative interviews using questionnaires and five cross-sectional studies gathered socio demographical and healthcare contact data for statistical analysis. Their aims were also varied: health seeking behaviour, beliefs perception, determinants of delay; biological factors ie. gender or age was noted.

Furthermore, researchers have also documented an association between poor educational attainment and a delay in seeking medical help, (Johansson et al. 2000; Needham et al. 2002; Salaniponi et al. 2000; Sudha et al. 2003). However, two other studies have documented no evidence of such an association (Ngmvithayapong et al. 2001; Odusanya et al. 2004).

A range of studies found self treatment to be a risk factor for diagnostic delay, (Thorson et al. 2000; Liefooghe et al. 1997; Yimer et al. 2005; Johansson et al. 2000; Npang et al. 2007; Togby et al. 2006). Again, a range of studies found self treatment to be a risk factor mainly from studies in OECD countries. The objectives of these studies were also varied: health seeking behaviour, beliefs perception, determinants of delay; biological factors i.e. Gender. (A full review of these studies provided in Annex 5: p.255-63)

iv **Socio-economic factors:** unemployment, cost of health care, work pressure

Studies have documented how low socio economic position in society (poverty) is contributory to a delay in seeking medical help, (Sarmiento et al. 2006; Grover et al. 2006; Ngamvithayapong et al. 2001; Johansson et al. 2000; Dos Santos et al. 2005; Van der Werf et al. 2006; Needham et al. 2002; Leung et al. 2007; Harper et al. 2003; Lienhardt et al., 2001; Sudha et al. 2003; Eastwood et al. 2004; Grover et al. 2006; Kasse et al., 2006).

Only one study from India identified work-related pressure and concerns about jobs (Sudha et al. 2003). Three studies identified being unemployed (Dos Santos et al, 2005; Leung et al. 2007; Van der Werf et al. 2006), and other poverty-related socioeconomic risk factors identified by two studies included cost of healthcare (Eastwood et al. 2004; Sudha et al. 2003) and not being able to afford the cost of travel.

B. Provider-related barriers

Studies that reported barriers associated with the providers' are determining patients' pathways to early diagnosis and treatment are grouped into three main categories of factors: quality, equity, and access issues.

i. Quality of care: sub-optimal care, delaying referral for tests, long waiting

Studies found healthcare providers particularly as sources of this vicious circle of visits to: primary-level government health posts and delaying pathways to diagnostic facilities by the doctors (Van der Werf et al. 2006; Needham et al. 2002; Macg et al. 2004; Watkins et al. 2004; Calder et al. 2000; Ward et al. 2001; Gerrish et al. 2010; Sagbakken et al. 2010; Marais 2007; Aye et al. 2010) and Storla et al's (2008) review. Poor performing unregulated private practitioners delaying referral (Macg et al. 2004; HO-M-J et al. 2004).

Six studies gathered healthcare contact data via questionnaire and from clinical record to generate their findings. Four studies explored patients experiences of illness, healthcare access to diagnosis and processes.

Other quality related risk factor identified by nine studies was delaying referral to diagnostic facilities by providers of care, (Kiwuwa et al. 2005; Liefooghe et al. 1997; Auer et al. 2000; Aye et al. 2010; Marais 2007; Leung et al. 2007; Paynter et al. 2004; Asbroek et al. 2008; Ho-M-J et al. 2004). Moreover, studies also highlighted low index suspicion and mésinterprétation of patients' symptoms by doctors, (Lienhardt et al.2001; Farah et al. 2006; Okur et al. 2006; Smith et al. 2006; Squire et al. 2005; Metcalf et al. 2007; Calder et al. 2000; Sagbakken et al. 2010; Marais 2007; Diez et al. 2005 ; Gerrish et al. 2010).

Interesting to note that five of these studies gave emphasis on healthcare contact time in the assessment of providers related barrier. Using a structured questionnaire with patients combined with data from clinical notes they were able to predict (conclude) a low index suspicion - misinterpretation of symptoms by doctors. Three studies while interviewed patients found that low suspicion of TB by doctors was a risk factor to delay. One of which interviewed patients and their GPs as well.

Studies also found being kept on treatment unrelated to TB, (Auer et al. 2000; Liefooghe et al. 1997; Asbroek et al. 2008; Watkins et al. 2004; Ward et al. 2001; Marais 2007; Goulb et al 2005) and delaying pathways to diagnosis and TB treatment. Three studies found suboptimal communication between GPs and patients and lack of continuity of care (Metcalf et al. 2007; Watkins et al. 2004; Gerrish et al. 2010). The two UK studies found that lack of time, increasing workload of GPs delaying the process of diagnosis for the

patients. Seeking care from private practitioners was due to professionals' attitudes in public services, (Johansson et al. 2000; Edington et al. 2002; Gibson et al. 2005)

ii   Equity of care: delaying diagnosis for women, uninsured, asylum seekers

The review also highlights that inequity of care against women and delaying their diagnosis which led women choosing less qualified health providers in five studies, (Thorson et al. 2000; Ngmavithayapong et al. 2001; Ahsan et al. 2004; Pronyk et al. 2001; Eastwood and Hill. 2004). Health seeking behaviour was the focus of these studies, gender differences and health seeking behaviour was specifically highlighted in three cross sectional studies. These studies gathered data on socio-demographic and healthcare contacts from the patients. However, it was important to note that two other studies from this group were able to reach their findings through interviews with the patients directly. Furthermore, lack of access to medical care for uninsured patients (Ngmavithayapong et al. 2001; Sarmiento et al. 2006) rural patients who were in need of hospital admissions, (Lawn et al. 1998). In one UK study the researcher found that GPs refusing to refer asylum seekers registered on temporary basis (Marais 2007). In another study in London, amongst forty-one TB patients who sought help from A&E units on many occasions before they were diagnosed, majority of patients 88% (n=36) had no access to a general practitioner (Smith et al. 2006).

iii   Access to care: proximity to health care, long waiting to specialist care

Studies found that access to healthcare as barriers of pathways to diagnosis and treatment associated with living at distance from healthcare, (Demissie et al. 2002; Sudha et al. 2003; Rajeswari et al. 2002; Maamary 2008; Needham et al. 2002; Huong et al. 2007). Moreover, once within the health care system patients also needed to wait long time before accessing specialist care, (Edington et al. 2002; Macg et al. 2004; Sarmiento et al. 2006; Lewis et al. 2003; Paynter et al. 2004).

Studies found healthcare providers particularly as sources of this vicious circle of visits to: primary-level government health posts have limited diagnostic facilities and poorly trained personnel, (Asbroek et al. 2008; Kiwuwa et al 2005; Rajeswari et al. 2002; Squire et al.2005; Watkins et al. 2004; Van der Werf et al. 2006; Macg et al. 2004; Meinntjes et al. 2008; Lawn et al. 1998; Aye et al. 2010; Calder et al. 2000; Farah et al. 2006; Ward et al. 2001; Nnoaham et al. 2006; Marais 2007; Sagbakken et al. 2010; Storla et al's review 2008; Metcalf et al. 2007; Okur et al. 2006; Goulb et al. 2005; Ho-M-J et al. 2004; Pronyk et al. 2001; Needham et al. 2001).

2.3   Discussion: a critical review of literature

The purpose of the review was to identify literature concerned with pathways to TB diagnosis and treatment in order to assess their relevance to patients' experiences. Overall the narrative thematic review of literature helps to identify potential weaknesses and strengths on findings from literature and assess the findings relevant to patients' experiences. In this only some non-UK literature have been selected in order to compare and highlight with the UK literature to present the critical discussion of results of this review.

2.3.1 Patient-related factors (Global Literature)

Studies reviewed have found healthcare seeking behaviour for TB is influenced by a patient's knowledge of TB symptoms, while others found low perception and lack of awareness of the severity of symptoms, a perception that the symptom is not serious enough to seek help, or a perception that symptoms are associated with smoking, or asthma, have also had an influence.

From studies reporting delay associated with personal belief and social stigma. Gibson et al's (2005) study in Table 2b correlated between health-seeking behaviour and perceptions of belief that patients have. They gathered data on socio-cultural factors using trained local interviewers. In their findings they observed correlation between lack of knowledge about TB, negative attitude and worse experiences of disease by patients. A key question is how the lack of knowledge and wrong attitude about TB are linked to worse outcomes of patients interviewed. However, from their findings stigma by health care staff, fear of isolation from family, poor knowledge and bad side-effects of TB treatment were experiences of aboriginal people interviewed related to healthcare rather than socio-cultural influences researchers sought to examine. The question and answer style of interview appeared to limit interviewees' ability to discuss their experience of stigma associated with medical help from professionals.

Npang et al's (2007) study in Table 2a investigated the influence of local beliefs and popular perceptions on cough and tuberculosis health-seeking behaviour. Twelve TB patients were asked to narrate their illness from onset of symptoms to the time of their interview. In their findings these researchers highlighted local beliefs, availability of wide treatment options for chronic cough and community misconception about TB as important factors that influence patients' healthcare seeking. However, the narratives of TB patients also revealed several trips these patients made to their health facilities before being screened for TB. This involved travelling from areas where there were poor geographic

accesses to healthcare. The researchers' findings appear to confirm what they sought to identify, that were related to community perceptions about TB in Rwanda rather than the real experiences of patients' pathways to diagnosis. It is also clear that the advantage of a less researcher-controlled approach in research by these researchers, i.e. using narratives to understand issues of health seeking from the patients have yielded insight into complex issues involving patients' journeys and their experiences of provider care.

Several studies have documented that help-seeking from alternative sources, i.e. private healthcare and traditional healers and also multiple contacts at same level, or with different providers before diagnosis. Amongst studies reporting delay associated with seeking care from alternate sources, findings from a number of studies suggest that women seek care from either traditional healers, or less qualified professionals. Thorson et al's (2000) and Pronyk et al's (2001) studies found that women choosing less qualified providers and were dissatisfied with qualified professionals' medical assistance. Interestingly Mammary et al's study found that not only living at distance from healthcare but also experience of stigma was reported by those who sought help from alternate sources. These factors found have yielded insight into complex issues involving patients related to their experiences of providers' care. The reason why they chose to seek care from less qualified professionals is not only due to gender however, studies did not fully explore this area.

Moreover, amongst qualitative studies low level education is associated with delay. Needham et al's (2002) study sought to clarify pre-determined factors delaying diagnosis. Using key variables from literature categorized their findings into six factors. Being female, low educational levels, and visiting private and traditional healers. Furthermore, Johanson et al's (2000) study analyzed data from focus groups using grounded theory approach and reported low level education amongst women, and also seeking care from private sector traditional healers and self treatment. Although their research focused on help seeking behaviour and gender differentials, they also found quality of care and professionals' attitudes were amongst factors women were very sensitive to. The obvious limitation of Needham et al's (2002) findings related to researchers' pre-determined variables of interests and may have limited their ability to induct key issues from patients' accounts interpretively that would have sufficiently explained women's real experiences.

However as the results of this review showed some studies reported inconclusive evidence on association of being female and being elderly and risk of delaying diagnosis. In regard to women and delaying medical help, the study by Ahsan et al. (2004) has found delay also associated with nearly 40% of women who were also dissatisfied with their providers. The patients' dissatisfaction with their care is unrelated to the socio-cultural problems these researchers have reported. This is consistent with findings of other studies

in this review which highlight how women found the providers' care does not adequately meet their needs for privacy and found healthcare professional attitude to their care inappropriate.

Sociological literature explains that patients from higher social class and higher educational level also tend to participate more in the consultation in terms of asking questions for explanations and clarification than patients from lower socio-economic background and educational level (Morgan, 2003). Taken together, on the one hand these findings suggest that users of TB service may have different pathways to obtaining help from a number of service providers, not only healthcare but also unqualified groups (healers). On the other hand what shaped their decision about choosing where to seek help may also relate to healthcare access and patients' prior experiences of professionals' care important but missing from the studies findings.

Studies have documented how low socio-economic position in society (poverty) factor is contributory to a delay in seeking medical help, as well as work-related pressure and concerns about jobs, being unemployed and living at a distance from health care, affordability of travel cost. Dos Santos et al's (2005) study reported unemployment and being treated in the two of the six districts in Recife as factors associated with delay. These researchers left unexplained in their analysis, particularly how differences in relation to the organization of services in six districts were compared in particular, staff attitudes and work practices; quality of work by health professionals. Although devoid of investigative detail, literature appear to suggest people in manual jobs, poverty and unemployment do lack access to medical help more often than their counterparts in employment and higher income groups (Morgan 2003:p.56-7). The lack of access to healthcare associated with living in poverty and delaying healthcare seeking was conspicuously missed in research reports trying to understand adequately why poverty and socio-economic issues interacted with medical help.

Sociological literature also explains that in doctors' consultation young people are more likely to expect a relationship of mutual participation than elderly people; doctors volunteer more explanation to some groups of patients, including more educated and also male patients (Morgan, 2003:p.57). It also contrasts with the clinical literature in which, in addition to consultation style, power relationships between the patient and doctors may affect clinical encounters. These are subjective accounts that studies had not been able to investigate. The reality about patients' experiences categorically analyzed using variables of themes or demographic characteristics, is missing important issues that may explain about TB patients and their experiences of access for medical help

2.3.1.1 Patient-related barriers (Local Literature)

Studies in the UK found differences in delaying seeking healthcare by the type of TB patients had. Patients with pulmonary TB were documented to have shorter delay than patients with extra-pulmonary form of TB. Reported patient total delay was from 9 weeks – 26 weeks for extra pulmonary TB (Lewis et al. 2003; Moudgil et al. 1994). This is a considerable length in contrast with other studies reporting patient delay by pulmonary-TB patients ranging from 29 days - 54 days (Paynter et al. 2004; Rodger et al. 2003). The second study, by Paynter et al. (2004) found that patient-delay is associated with migrants who sought care from A&E had delayed more (median patient delay was 54 days) than those who sought care from their GPs (median patient delay was 30 days) and reasons for these differences is not clear from their work. However, no association found in the study by Rodger et al. (2003), more delay reported in white and being female accounted for delay of 72 days rather than Black and Indian sub-continent or migrant which accounted only for delay of 43 days.

Although these studies shed light on time length taken to contact health service by patients, reasons for differences with regards to patients' choices and experiences of either GP or A&E care seeking are not provided. A retrospective analysis of clinical records and follow up questionnaire surveys with clinicians are too limited to identify these key issues and the accuracy of data and analytical truths may be questioned. As a result, research focused on individuals' demographics and time taken for seeking health care, involving large participant groups may only identify groups who may have been delayed longer, but cannot adequately explain underlying patients' factor, that may be linked to the providers of healthcare.

Amongst qualitative studies, Nnoaham et al's (2006) study found significant differences in delaying TB diagnosis, ranging from two weeks up to forty weeks among the 16 African patients they interviewed. Amongst factors found are: perceptions of symptoms, misconceptions concerning disease etiology, symptom misinterpretation and linking symptoms to food poisoning and heavy workloads and denial of diagnosis. While illness misinterpretation, denial and stigma could account for reported delay, in 9 of the 16 patients interviewed who had delayed over four weeks before health care contact, their experience of factors found and reported delay is not sufficiently described to demonstrate associations. Their aim focused on community perception about TB to some extent influenced a range of issues explored but not linked to reported delay in TB diagnosis. However, the extracts of three patients highlights misinterpretation of symptoms by their doctors accounts for diagnosis delay of 4, 10 and 16 weeks that was conspicuously missed as key to their findings.

2.3.1.2   Critique of Literature

The thematic review of literature highlighted what and how studies have sought to investigate barriers to diagnosis and treatment. By and large, studies have assessed time length taken to healthcare correlated with the patients' demographical, socio-cultural and economic variables to depict patient related delay as a storyline.

The thematic approach in this review also highlighted limitation of studies in identifying the patients' accounts of their experiences of medical help. Where the researchers' emphasis is on patient-related behavioural, socio-cultural, biological factors for delaying diagnosis, their findings also highlighted problems associated with providers' care that were not sufficiently explored. This appears to signify how, invariably, health behaviour interventions were directed at patients without scrutinizing the providers of care (Cohen, 1997:p.81). The patients who experienced difficulty in accessing healthcare for medical help may have been reported as responsible for delay. The lack of definition as to what constitutes healthcare contact brings into question how these researchers have accounted for likely bias in the analysis of data.

Even so, the findings from studies are informative, literature on assessment of patient-related barriers failed to recognize the multiple ways in which the medical help is organized. As Weisbord (2004) notes that 'understanding patients' behaviours is fundamental to design communication interventions ... to assist in identifying these barriers it is useful to then map out along a preferred behaviour continuum from the first sign of symptoms (cough) to treatment completion (cure), (p.7). In this review most studies emphasised more on behavioural aspects and failed to look into providers' communication issues, and as a result their findings are unable to capture fully factors associated to healthcare.

2.3.2 Provider - related barriers (Global Literature)

Literature focus on provider-related barriers to delay is sparse, highlighting mainly time taken from diagnose to starting TB treatment. In this review barriers associated with providers of care highlighted by some studies despite their aims were intended to identify barriers associated with the patients. (see narrative review data synthesis in Annex 5) This is reflected in Waisbord's (2004) review of behavioural studies on patients' pathways delay which concurs that the lack of diagnostic tools in health clinics, bad implementation of care, overall underutilization of healthcare services; oversight by health care providers (due to insufficient knowledge of TB and neglect) are plausible explanations for the diagnostic and

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system delays associated with health systems' (2004). The section below will look into this particular issue in more detail.

Studies found healthcare providers particularly as sources of this vicious circle of visits to: primary-level government health posts have limited diagnostic facilities and poorly trained personnel. Storla et al's review found the theme of 'vicious circle of repeated visits at the same physician level or with multiple visits at the same health care providers without a correct diagnosis', (2008) of the direct or underlying problem. In Asbroek et al's (2008) study patients' accounts of health seeking behaviour and their encounters with the healthcare often involved multiple contacts with providers and lack of providers' initiated referrals. Self referral by patients due to lack of trust in the provider was found to be very common. Referral to diagnostic testing by providers was prompt when tuberculosis was considered a possible diagnosis by both private and public health care providers.

Interestingly amongst cross sectional studies Ward et al's (2001) study also found that healthcare providers' failure to perform appropriate investigation, misdiagnosis of illness, ineffective treatments in repeated patients' contacts of healthcare involving 750 smear positive patients. Evidently some qualitative studies that employed predetermined theoretical ideas in their investigation, their findings appeared to reflect on what they sought as barriers rather than identifying the real issues from the patients themselves. In most cases, the focus of research appears to be a key influence on the studies findings as highlighted in a number of studies in this review.

Poor knowledge of TB and professionals' low index suspicion and misinterpretation of patients' illness symptoms were highlighted by sixteen studies. Of these studies the methodology most frequently reported for eliciting patients' experiences of poor quality care from professionals are interviews, (face-to-face semi-structured or in-depth) and data from clinical-notes. Sixteen papers reported delay associated with misinterpretation of TB symptoms. Three of the papers are from the UK but only one sought to examine the diagnosis process involving patients and their GPs, discussed below.

Studies found inappropriate handling of patients' concerns and misinterpretation of symptoms, Squire et al's (2005) critical narrative analysis of lost smear-positive patients' pathways to diagnosis and treatment was able to trace the addresses of nineteen cases and able to interview five patients and the careers of the remaining patients who had died of the disease. Listening to the story of patients' experiences of pathways from their discovery of TB symptoms, healthcare they had visited, consultations and treatment they had received: revealed inappropriate handling of smear negative TB suspects; delays between sputum submission and test results; misinterpretation of symptoms by health workers and lack of ambulatory TB treatment facilities as barriers to starting TB treatment.

This was consistent with Storla et al's (2008) conclusion based on their review of factors contributed to delay associated with cycle of contacts by patients to providers. This is also highlighted in this review amongst studies from non-OECD countries (see Table 2a) gender inequity in health care, e.g. women diagnosed late by healthcare providers and dissatisfied with the attitudes of healthcare workers, poor quality of care and their knowledge about TB. Squire et al's findings are useful because it highlights a number of provider-related barriers experienced by patients. The 'inappropriate handling of TB suspects and smear negative patients; delays between sputum submission and test results; misinterpretation of symptoms; lack of ambulatory TB treatment facilities (hospital admission and attendance as a barrier to care) from stories told about patients' pathways, (Squire et al. 2005).

2.3.2.1 Provider - related barriers (Local Literature)

Amongst qualitative studies in the UK four studies have highlighted the same theme of repeated contacts by patients prior to diagnosis. These studies varied in their research focus: community perception about TB through in-depth interview with patients Nnoaham et al. (2006), diagnostic processes in primary care semi-structured interviews with patients and their GPs Metcalf et al. (2007) and socio-cultural influences, Gerrish, et al. (2010) structural and healthcare professionals' related barriers through semi-structured interviews with patients, (Marais 2007).

Nnoaham et al.'s (2006) and the Marais studies undertook their research using predetermined theoretical ideas, in which their findings are related to what they thought of as barriers rather than identifying the real issues from the patients themselves. This is demonstrated in the partial representations of the patients' pathways to diagnosis and treatment. Sufficient details of the chronology of patients' contacts with healthcare from their accounts would have revealed interesting results as demonstrated in the Squire et al's (2005) and Sagbakken et al's (2010) findings of patients' experiences of their healthcare.

However, Metcalf et al's (2007) study highlights that the patients' experiences of pathways to TB diagnosis involve numerous contacts made by the patients to their GPs. The authors' findings in relation to patients' accounts revealed that lack of continuity of patient care by GPs and the GPs' consultations did not seek to identify the patients' health concerns. Most patients felt that they were not listened to; their concerns about the risk of TB were not taken seriously by their GPs resulting in misunderstandings between the patients and their GPs. Many of these factors associated with the providers described as: atypical presentation and low suspicion, lack of continuity of care, sub-optimal doctor-patient communication, workload demand; lack of continuity of care, (Metcalf et al. 2007).

In a close review of the UK studies, on the one hand, the study by Metcalf et al (2007) in Wales and Marais's (2007) study in Westminster in London have not clearly described the length of time taken by providers for all patients they interviewed. In the Metcalf et al's study, there were three represented case stories where the patients presenting symptoms have been mis-diagnosed in a number of contacts: the first was a spine TB case who had made six contacts over a period of a year. The second was a TB meningitis case who had made three contacts to the A&E and four contacts with her GP before diagnosis. The third case was a classic pulmonary TB case who presented herself six times to her GP over a period of five months before her diagnosis. As noted earlier the Nnoaham et al. (2006) found weaknesses, some extracts from patients presented in their report associated with providers' failure to diagnose was unexplored by researchers. Although researchers' findings on provider-related barriers are useful, the representation of storyline did not clearly highlight this in their report. It would also have been appropriate to describe clearly the delay found as total delay rather than patient delay.

Two studies, Paynter et al's (2004) and Smith et al's (2006) studies, examined clinical notes looking at the patterns of delay retrospectively and reached the conclusion based on their evaluation of providers' clinical notes. Paynter et al's (2004) study reported median provider delay of 49 days by GPs and median delays of 4 days by hospital A&Es. All patients who had attended A&E first, were born in a high prevalence country and clinicians were likely to have high suspicion of TB prompting clinical investigation. In regard to longer delays associated with patients seen by GPs: waiting for results from investigations, particularly chest X-rays and waiting times for chest clinic appointments were reported as factors. It was reported that median delay between GPs' referral to chest clinic and patients' attendance was fourteen days (attributed to shortage of staff capacity in chest clinics). The median delay from a GP request for chest X-ray to the GP sending a referral to the chest clinics was nine days (attributed to delays in radiology and primary care) (Paynter et al. 2004: p.184). Smith et al.'s (2006) study from analysis of A&E attendance found that amongst forty-one TB patients presenting to A&E thirty-six patients had no GP and all forty-one patients attended A&E on many occasions six months before they were diagnosed. Smith et al's (2006) findings seem to highlight different sets of finding from Paynter et al's (2004) findings of quick access to specialist diagnostics in those presenting in the A&E, compared with those patients attending their GPs. Although researchers' findings on A&E - related diagnostic delays are useful, the representation of data did not clearly provide sufficient details about the patients' GP registration status and the number of A&E contacts made by each patient who sought help from A&E units.

Clinical data are mostly records of past events and tend to reflect on partial and incomplete medical encounters. This has limitation on its reliability and validity and it is

unlikely to reflect patients' experiences of their clinical encounters. Face-to-face interviews with the patients however are a relatively better and effective way of generating chronology of events from patients themselves interpretively. This approach has been used particularly for understanding the chronology of events leading to diagnosis and treatment retrospectively through storytelling in Squire et al's (2005) investigation in non-OECD literature. (see Annex 5) Although there are differences in sources and types of data used by UK studies, these differences are reflected on method and data sources and types in analysis and reporting. Although these studies highlight the sources of diagnostic delay for the purpose of this review, the accuracy of Paynter et al's and Smith et al's findings can be questioned due to case notes and surveys limitations on providing either the content or contextual understanding of patients' experiences of their pathways.

2.3.2.2 Critique of UK Literature

Amongst studies which have looked at the routes to diagnosis and treatment, Metcalf et al's study (2007) the interviews also involved GPs and the Marais (2007) study involved wide participant groups: community consultations with migrant communities; stakeholders and interviews with individuals with history of TB treatment. In both studies the representation of data, the full accounts of patients interviewed appear to be overshadowed by the researchers' emphasis on processes and structural influences on TB control. As a result, many of the contexts and content of patients' experiences in relation to the timing of diagnosis and treatment were inadequately represented. Furthermore, on factors found to contribute to delay the accounts of GPs have been highlighted more in order to explain about problems associated with primary care in the Metcalf et al's (2007) study. The processes of inappropriate handling, delays between test results; barriers to TB treatment (Squire et al. 2005), access and availability of services quality of a provider; delayed referral, (Asbroek et al. 2008) may also be important and that was not fully captured in their findings due to emphasis on processes rather than patients' accounts of primary care associated delay.

With regard to methodological designs, these studies differ in their research approaches. Metcalf et al's study applied semi-structured interviews, no details on how the researchers framed their research questions or specific details about the analysis strategies they have employed. Nnoaham et al (2006) applied in depth interviews; interview questions were generated using Kleinman's explanatory model of illness and in analysis a grounded theory approach was used. In both studies, their contribution to knowledge on the topic is also limited in some ways. The limitation of Nnoaham et al's (2006) study was that due to

researchers' preset theoretical assumptions, the research was unable to induct new data. This could have been the reason for not exploring factors related to providers' care which emerged from the data. Metcalf et al's (2007) study suffered from a lack of clear methodology and analysis strategy, potentially 'non-empirical' as it lacks focus on how to account for evidence gathered from the data. Moreover, with the apparent tension between the understanding of diagnosis process in primary care, patients' accounts, and views of GPs to understand the process of diagnosis in primary care, themes inducted were not clearly related to severity of delay highlighted in the patients' accounts of diagnosis and treatment processes. Marais's (2007) study is 'empirical' but suffered from lack of depth in providing sufficient detailed contextual understanding of the experiences of all TB patients involved in the study. The researcher's emphasis on preset theoretical variables linked to numerous structural influences involving multi-stage PAR projects may seem to limit the depth of evidence it generated. It would have been important to indicate key dates of healthcare contacts and medical help provided for eleven patients interviewed rather than presenting the extracts of four patients.

2.4 Reflection on Review Process and Key Learning

The findings of this review indicate diversity in studies' methodological designs, aims, data sources, analysis and findings which were informative in many ways which reveal the potential weaknesses and strengths of this current study. The choice of using a narrative rather than a systematic review was consistent with understanding meaning from narratives, (Riessman 1993: p.21). In reading papers for what was said – I looked into what the researchers have said about the purpose of their study. In looking at meaning from narrative – I looked into how data was derived, and structured. I then looked into what was specifically reported from findings in order to assess the relevance to the topic for this review. The thematic synthesis of literature highlights the patients' misjudgements of symptoms (thinking not serious), choosing self-treatments, work-related concerns and pressures. Providers' care quality, equity and access issues were useful to patients' experiences of barriers of in their pathways to diagnosis and treatment.

However, this review has limitations as extensive searches could not be carried out on qualitative studies applying a range of search methods and key databases. I did not exclude studies based on methodological design and quality, because the rationale was to understand from review what and how studies have sought to understand and what they were able to find with the purpose to highlight gaps in literature this research has sought to fill in.

Key Lessons Learnt?

- One of key lessons to be drawn is how the researchers' pre-determined objectives influenced what the researchers wanted to gather and also report, rather than on the key issues highlighted by patients involved (Muela-HS et al. 2003: p.18).

- The narrative review of studies depicts one aspect of master-narratives that perpetuate patient-related delay while the voices of patients are given less emphasis in research. Evidently the patients' accounts of chronology of events associated with either themselves or their care providers could not be captured in the majority of studies.

- One other lesson is that the limitation on the UK literature aims to increase knowledge of diagnosis processes, community perceptions, structural factors, and A&E attendances appear to provide a partial picture of patients' journeys. As Waisbord (2004) notes that, understanding patients' behavioural and societal [structural] barriers, it is useful to map out the continuum from the first sign of symptoms (cough) to treatment completion (cure).

- Another lesson is that conventional research approaches of using pre-set structured questionnaire (questions) that aim to understand complex issues involving patients' health seeking behaviour appear to influence the data types, analysis and research findings. In a less researcher controlled approach patient-centred stories appear to capture patient-related and provider-related barriers more fully.

- Review of studies highlights that age, sex, employment, ethnicity, Type of TB, occupation, 1st symptoms manifestation, date of first contact, source of 1st help sought, date of health care contact, date of diagnosis, date of TB treatment were used widely in literature to predict factors delaying health seeking behaviour. As highlighted in the review there seems to be little benefit in predicting delay using these sets of variables without patients' accounts of their experiences of time, contexts and content of their medical help.

- An important lesson to this study is that those studies that focused on patients' pathways to diagnosis and treatment based on patients' interpretive accounts of events were able to provide more useful details of patients' experiential accounts of their journeys.

2.4.1 Making a case for the study: benefits of 'story-telling' in research

In Chapter one, I discussed the experiences of five different stories of patients, two of whom published in a local newspaper. These two personal stories highlight issues where research failed to uncover the perspectives of patients surrounding their health care services, particularly in London.

The first story is from a young woman called Amy McConville, age 25, a law student at Sussex University. Amy first experienced TB symptoms in September 2004. Her persistent cough led to many consultations with her GP and local hospital for over a year.

Despite many contacts with health professionals, her TB was not diagnosed until January the following year. According to the story it was her uncle who thought it could be TB who triggered the discovery of her TB. During this time, the disease had spread into her lungs and her left lung was severely damaged and needed surgery to remove her lung in order to cure her.

The second story was Carl Liebel, age 24 year, a city bank employee in London. It was in August 2005, when Carl developed a cough on a trip to Sweden. On his return, Carl contacted his GP as he was ill and hardly able to speak. He was coughing and losing his appetite. His GP thought the illness was related to laryngitis. However, Carl was coughing a lot, sweating at night, unable to eat or sleep. According to the story producers, Carl's condition was deteriorating while he was still under the care of his GP. Subsequently, his father had suggested that Carl go to Australia and seek treatment from his (the father's) GP. He eventually did go and the Australian doctors diagnosed the worst TB case that had not been detected and kept him in isolation. He was then offered treatment but realized that the treatment was likely to cause side effects which might lead to hearing loss. Although Carl was already losing faith in doctors due to his very bad experience in the UK, he eventually returned to the UK and sought treatment in London to achieve full recovery and cure of his TB.

These two stories are a representation of summarized stories by newspaper editors who did not cover the stories in great detail. However, both cases exemplify the complex interplay that occurred between these patients' illnesses and their experiences of healthcare in London. Both cases have particular relevance to issues highlighted in this review. The barriers associated with providers of health care pathways to diagnosis. Nevertheless, the Newspapers' versions of stories, particularly stories of this nature, are a form of representation based on fact, but they may be written to attract readers' imagination through what has been called rhetorical narrative (Lucaites et al. 1985:p.97). They are mostly presented using powerful editorial language to persuade/invite readers. Narrative enquiry in this research has kept the accounts of research participants unaltered, paying attention to chronology of events: in relation to time, context and content of story tellers' experiences (Riessman, 2008). This is how this thesis seeks to inform its readers by representing as many details as possible about the context and content for reinterpretation.

2.5   Summary of the chapter

In the review of two master narratives, the literature is organized to illustrate provider-related and patient-related diagnostic delay. The review purpose was to identify literature concerned with pathways to TB diagnosis and treatment in order to assess their relevance to patients' experiences. The chapter provided a narrative review of literature.

The chapter highlighted how the narrative thematic review of literature helps to identify potential weaknesses and strengths in findings from literature and assess the findings relevant to patient experience. I have highlighted key lessons from the global review of literature and discussed the methodological weaknesses in research to understand factors associated with patients and providers of medical help. This is because neither the surveillance, nor the theory driving qualitative research is able to capture fully the complexity of pathways to TB diagnosis and treatment experienced by the patients.

I have discussed how the focus of research in London only provided a partial understanding of patients' experiences of barriers either related to themselves or their providers. I have also presented cases to demonstrate how patients' stories attract the headlines of local newspapers and cases of court litigations highlighting complexity of their pathways to treatment to highlight the significance of the problem. The chapter also presented the case as to why a narrative enquiry as a method offers better understanding of patients' experiences. Key lessons learnt from the review also indicate how focusing on patients' pathways, from initial illness to diagnosis and treatment, provided a better advantage to understand the perspectives of patients' and barriers more fully.

In the chapter that follows, I will describe the processes I have undertaken to drive the thesis research questions and the method of this research in detail.

Chapter Three   Research Methodology and Method:
Narrative Enquiry

3. Introduction

This chapter will begin with a brief outline of the study settings rationale; the description of the pilot study within which the research questions generated and method was tested to operationalise this research. The research methodology and key philosophical and theoretical underpinnings of the method are discussed. The remaining part of the chapter will present the research method, the data collection procedures, the thesis questions, analysis of the data procedures. The steps I have undertaken in order to address quality in the representation and analysis and the rationales of the method and limitations and challenges are also discussed.

3.1   Study settings, descriptions and rationales for site selection

The study was undertaken in three boroughs of London. Two of these boroughs, Newham and Brent, have the highest notification rates of TB in UK as a whole with an incidence rate of >100 per 100,000 population, (HPA 2010: p.39 – 40). Fig 7 shows that areas affected by TB also have the highest deprivation scores. The preliminary choice of sites from the boroughs of London was based on the severity of their TB burden.

Newham is located in the north-east central London (NECL) TB sector. It has the highest level of homelessness and HIV/AIDS in East London, 61% of its population is black or from an ethnic minority and it is the 5th most deprived borough in England (HSC 2005). The borough has the highest TB notification rate in London and in UK as a whole; 88.23 per 100, 000, in 2005; which increased to **117 per 100,000** population in 2009 (HPA, 2010: p.40). The Newham Teaching University Hospital Trust (NTUHT) is a key provider of TB services for Newham. (see Fig 7)

Brent is part of the south-west central London (SWCL) TB sector. One third of TB patients are UK-born in Brent, (Brent, 2004), while 51% of residents are Asians and black Africans. In Brent TB mainly affects young adults and new arrivals; black Africans and Asians have the highest rate of TB (Brent, 2004). This borough is the 11th most deprived authority in England and has the second highest TB notification rates in the country. The TB rate increased from 93 per 100,000 in 2005 to **109 per 100, 000** population in 2009, (HPA, 2010:p.39). This borough puts a strong emphasis on minimizing the risk of delaying the diagnosis and treatment of TB and on tackling stigma and access to health care which are

key public health issues. The Middlesex University NHS hospital Trust is a key provider of TB services for the borough and the surrounding areas.

Fig 7: TB notifications rates and Deprivation Scores of Study Areas (Source HPA)

Tuberculosis notification rates   Index of Multiple Deprivation Scores
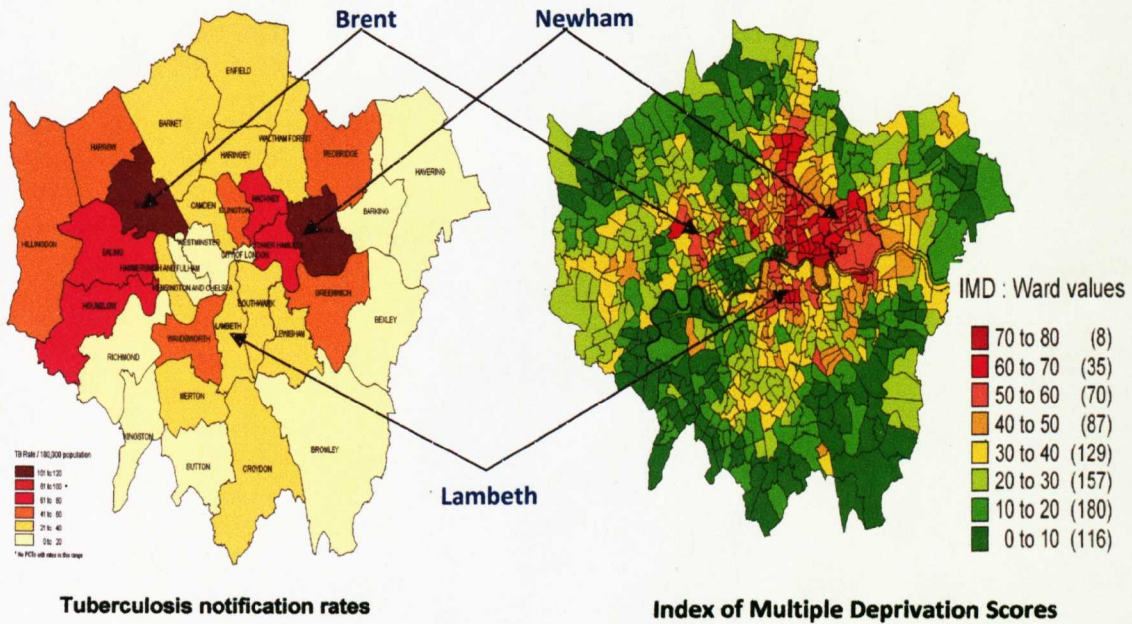
Lambeth is part of the south east central London (SECL) TB sector, 24% of its residents are born outside the European Union (EU), it has the highest in-flow and out-flow of migrants in London and the highest rate of HIV / AIDS in south-east (SE) London, mainly among people with Black African backgrounds (Lambeth PCT, 2005/6). In this borough 38% the population is of a non-White ethnic background. The borough TB notification rate in 2004 was 47.7 per 100,000, in 2009; which declined to 42 per 100,000, (HPA, 2010:p.40). The Guy's and St Thomas's NHS hospital Trust is a key provider of TB services for the borough and the surrounding areas.

The diverse demographic location in London provided an opportunity to explore the varied and contrasting experiences of TB patients' access to TB diagnosis and treatment in differing contexts of healthcare delivery.

3.1.1 Ethical Approval and Registration

In December 2008 I began the application for ethical approval from the Research Ethics Committees (REC). Ethical approval from the St Mary's Research Ethics Committee London and from the London School of Hygiene and Tropical Medicine Research Ethics Committee was obtained in January 2009. (See Annex-1) This research also needed approval for its registration from the Guy's & St Thomas's Ethics Governance and the Newham University

Teaching Hospital Trust; the Brent PCT, the Lambeth PCT and the Newham PCT Research & Development Governance units. (see Annex 1)

3.1.1.1 Ethical Guidance for Research

Final ethical opinion and guidance from St Mary's REC referred to three issues in particular; the purpose of the interviews; the selection of the research participants and the use of interpreters for non-English speaking volunteers. The committee's advice was that interviews with the participants' should focus on their experiences of obtaining medical help and that no other subject should be discussed. With regard to the selection of research participants for the study, the committee advised that physicians would be able to identify suitable volunteers and refer them to the researcher who was also present in the clinic setting. It was also made clear that the use of interpreters for interviews should not involve the patients' family members or friends. Instead independent professional interpreters should be used if and when the interviewees agreed to such arrangements. These requirements were complied with in full in this research.

The NHS ethical guidance for research states that "the arrangements for informed consent in research must be based on adequate information and must be voluntary. Consent may be in writing and must include a copy of a participant information sheet explaining the nature of the study. There must be sufficient time in which to answer questions that might be raised by the research participants. The circumstances should be conducive in order to enable the participants to consider the full implications of taking part in the study.",(NRES, 2007).

The elements of informed consent were addressed in this research as follows. Even though each participant had an adequate understanding of the nature, purpose and implications of his/her participation in the research, there were concerns associated with obtaining informed consent in a busy clinic environment as a result of the wait for follow-up treatment. Being sensitive to these circumstances, each participant was given the option of arranging the interview during their follow-up visit to the clinic. All of the participants were provided with information sheets, the content of which was explained. The participants were given the opportunity to ask questions about the research before giving their consent. For non-English speaking participants, professional language interpreters were used and sufficient time provided for them to give their informed consent. At all times, the interviewees were assured that any information which was collected pertaining to them would not be shared with anyone without their permission. All of the participants' voice (audio) data, consent forms and personal details will be retained for three years before being disposed of.

This is in accordance with the requirements set out by the LSHTM Ethics Committee's guidelines and was agreed upon by the St Mary's Research Ethics Committee.

3.1.2 The Pilot Study: focusing and locating this research

Ethical approval and permission was obtained from chest physicians to undertake an exploratory pilot study. The pilot was conducted between May and July 2009 within three chest clinic settings: in the St Thomas's hospital in Lambeth, Willesden Health Care in Brent and Shrewsbury Road clinic in Newham. The pilot involved in-depth interviews with ten TB patients who were on treatment. (see Table 3) On completion of the pilot study, a written report was disseminated to all chest clinics doctors and nurses. (Full pilot report in Annex 2)

Table 3 Characteristics of pilot participants and healthcare Contacts

Patient	1	2	3	4	5	6	7	8	9	10
Age	24	27	34	28	29	51	41	18	18	40
Sex	M	F	M	M	M	M	M	F	F	F
Birth place	Pakistan	India	Pakistan	Nepal	India	Ethiopia	Ethiopia	UK	Somalia	Somalia
Known TB contact	Cousins Pakistan	Not known	Friend London	Live with TB case	Not known	Not known	Not known	Not known	Friend London	Not Known
Type of TB	P.Tb	G.Tb	G.Tb	O.tb	P.Tb.	P.Tb	P.Tb	P.Tb	S.Tb	A&GTb
First HC contact	GP	Priv. HC	GP	Priv. HC	GP	A&E	A&E	GP	GP	GP
Date of HC contact	Dec, 08	Feb, 09	Feb, 09	Mar, 09	May,08	Dec, 08	Dec, 08	May,08	Apr, 09	Oct, 08
Diagnosis	May, 09	Feb, 09	May, 09	Mar, 09	Feb, 09	Dec, 08	Dec, 08	Jun,08	May, 09	Feb, 09
TB treatment started	May, 09	April, 09	May, 09	Mar, 09	Feb, 09	Dec, 08	Dec, 08	Jun,08	May, 09	Feb, 09

keys :
P.Tb – pulmonary TB   A.Tb- abdominal (Peritoneal) TB   G.Tb - Glandular TB   S.Tb – TB in Spines
O.Tb – TB in the retina (eye)   GP – General Practitioner   HC- Healthcare   Pt. –   patient

Results: The major experience that was consistent in the pilot interviewees' story relates to the delayed access to diagnosis in London, particularly in the pre-diagnostic care pathways from GPs and also for some hospital ambulatory patients referred by GPs and by private doctors. The theme[11] of 'miscommunication' featured in pilot interviewees experiences were: 1) Misinterpretation of TB symptoms by their GPs.   2) Being on treatments from GPs that had no benefits, e.g. painkillers. 3) Inappropriate referrals for tests

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[11] According to Denzin & Lincoln, themes are abstract (and often fuzzy) constructs found in the texts and also in images, sounds and objects. As constructs they define the expressions and actions of informants. In social science researchers can induce themes from the data or develop them from the background literature. In a careful line by line reading of the text, looking for assumptions, consequences, presence of repetition of words, and looking for metaphors people often use to describe their thoughts and behaviour are ways of identifying themes from the data, (2000: p.780-81).

by the GPs, unrelated to their expressed illness. 4) Long delay for hospital appointments and repeated diagnostic procedures ·

The pilot study was useful to provide insights into the feasibility of narrative enquiry method and to refine the data collection and analysis techniques for this main field research. The outcome of the pilot study in part contributed to the thesis research questions to focus on: TB patients' experiences of pathways to TB diagnosis and treatment in London. As noted in the preceding chapter the focus on this issue has been highlighted as one of the key learning drawn from the review of literature. I also like to note that my advisory committee members' view was that, rather than a focus on themes discovered in the pilot, giving attention to the chronology of events, time, the context and content of participants' experiences of medical help through in-depth narrative interviews was more workable using a narrative enquiry method. In the section that follows I will begin with the description of the methodological approach of this narrative research.

3.2   Methodological foundations of narrative enquiry

Narrative turn or narratology is a new development in the social sciences and a research orientation involving a narrative ('the story itself') as the object of investigation (Riessman, 1993:p.1). According to Riessman, narrative enquiry is grounded in the study of the particular, and researchers are interested in how a speaker assembles events in a sequence and uses language to communicate meaning, that is, how the speaker conveys particular points to an audience (1993:p.11). Narrative enquiry shifts from looking at representations of the research subjects from a distant standpoint and focuses instead on narrator-interpreter relations, context, and the narrative form-topics being explored (Riessman 2008:p.16).

The core paradigm of narrative research recognises research subjects (which are themselves interpretive), interpretive accounts which are also developed by an investigator based on interviews (a story about stories), and even the narrative report which a reader constructs after engaging with the participants' and the investigator's narratives (Riessman, 2008:p.6). This illustrates the epistemological basis of the narrative enquiry in this research. It draws on the key premise of social constructionist thinking that assumes the many forms of interpretive accounts based on the 'subjectivist paradigm' rather than looking at interpretation from a fixed viewpoint as adopted in the 'positivist paradigm'.

This is because narration can no longer be seen as a straightforward representation of reality (Crotty, 1998:p.64). The social constructionist standpoint is relativist – it assumes that the reality and knowledge of it are products of particular social, political and historical contexts that are changing (Green and Browne, 2005:p.19) and different perspectives of reality or truth that can be known. In narrative research, 'the historical truth of an individual's

account [story] is not the primary issue. Narrativisation assumes point of view. Facts are products of an interpretive process; facts and interpretations require and shape one another", (Riessman, 1993:p.64). In narrative research, the primary issue is the construction of meaning the story teller tried to convey about her/his experiences to the researcher (Riessman 2008).

In research, the construction of meaning from narrative is a way of organizing accounts of actions; bringing together mundane facts; and time and place are incorporated, (Sarbin, 1986 – in Riessman, 2008:p.9). By focusing on, 'what was told' and 'how the story was told' by participants solely through their imitations (mimesis) of their experiences, (Riessman, 2008: p.22). The researcher is taking part in a joint construction of stories and interpreting the "storyteller" (Reissman 2008:p.17). Cheryl Mattingly notes the mimetic position of the researcher in constructing narratives that are event centred ... unwilled, unpredicted ...by actors [patients] themselves, (1998: p.8). Attwood and Grace (1999) adds that:

> 'When you are in the middle of a story, it isn't a story at all, but only a confusion; a dark roaring, a blindness...a boat crushed by the icebergs or swept over rapids and all aboard powerless to stop it. It's only afterwards that it becomes anything like a story at all, when you are telling it, to yourself or to someone else." (In Hurwitz et al. 2004: p.52).

The contexts of the construction of meaning are explained below

3.2.1 Theoretical Contexts: Representation of Experience

Narratology (an object of knowledge) within the field of social sciences recognises storytelling as a way of gaining an understanding of the way in which individuals construct meanings for their experiences (Riessman 1993:p.1). A narrative 'representation of experience' theoretical context has been used to guide this research. Riessman proposes that the 'representation of experience' involves five simple (but important) stages: 'attending'; 'telling' (by the research participants); 'transcribing'; 'analysing' (by the researcher); and 'reading' (by the reader of the research reports) (1993:p.10). A brief discussion of these key constructs below will provide the framework and basis for the research method applied in this research to answer the thesis research questions.

3.2.1.1 Attending to experience
Firstly, when attending to experience, the storyteller (the interviewee) is required to recall: his/her awareness of events; his/her reflections; what he/she remembers and his/her observations and recollections. The assumption is that the teller has access to the events that he/she has experienced: the context and content of his/her experiences are elements of

the story's creation. During the story construction, the storyteller interprets her/his memories and memories, which serve as personal creations (Lieblich et al. 1998). This process requires paying less attention to question-answer exchanges, concentrating more on how the interviewee connects his/her sustained account of his/her story to the interview topic, (Mishler, 1986 as cited by Riessman, 1993:p.16) in other words, the storyteller-led conversation is applied in narrative research.

3.2.1.2. Telling about experience

Secondly, telling about the experience involves detailing events that are already ordered to some degree, in the form of discourse (Riessman 1993: p.9). The process of telling involves a 'teller' and a 'listener', who hold an exchange in order to clarify the feelings and emotions in the teller's narrative construction (Cottle, 2002). The role of the researcher is to unearth the knowledge buried within the topic of the interview (Kvale 1996 as cited by Giovannoli, 2000:p.30). The engagement of the teller and the listener is conjoined in the process of constructing meaning and narrative (Riessman, 2008:p.31).

3.2.1.3 Transcribing the experience

The third level of representation is when the researcher transcribes the teller's experience, converting conversational speech into text. In qualitative research, a thoughtful investigator does not assume that language is transparent (Riessman, 1993:p.12). Instead, the researcher attempts to transcribe conversations in a way that best captures 'the rhythm of the speech: silences; false starts; emphases; and nonlexicals like 'uhm', [and] discourse markers like 'you know' or 'so' (Riessman, 1993:p.12). Transcription is the form of representation that reflects the researcher's interpretation, which is 'incomplete, partial and selective' (Riessman, 1993: p.12). The choices on 'what to include' and 'how to arrange and display the text' have implications for how the reader understands the narrative, (Riessman, 1993:p.12). Transcribing is therefore relative to the researcher's aim (the research question and purpose of investigation) and particular research philosophies and traditions.

3.2.1.4 Analysing experience

The fourth level of representation is the analysis of the teller's experiences by the researcher, which involves his/her engagement with the degree of reciprocity in the conversation (Riessman, 2008: p.24). Analysing the teller's experience involves not only the content of what was said, but also why the story was told in a specific way (Riessman, 1993: p.2). A story about experience has three core functions: *'the ideational function'* (the referential meaning of what is said), which is the content of what the teller has said about his/her experiences; *'the interpersonal function'*, meaning the relationship between the teller

and the listener, which creates a medium for the expression of the teller's personal story (who makes sense of events and works to convince the teller's listener of the story) through his/her expressions; and 'the textual function' refers to parts of the texts that are connected synthetically and semantically, and reveal how the story is told. Analysing experience is, therefore, related to meaning at all three levels of interpretation – 'what is told' and 'how it is told' – within the context of the exchange between the teller and the listener' (Riessman 1993: p.21-2).

3.2.1.5 Reading experience

The fifth level of representation is the reader encounter that is the written report of the teller's experiences. The written report is a form of representation of the researcher's meta-story of the experience of the teller (Riesman, 1993: p.13). According to Bruner (1986) as cited by Riessman (1993: p.14), 'the reader of the report is an agent of the text' and written texts are created within and against particular traditions and audiences and these contexts are brought to bear by the reader'. The assumption in this is that culture; experiences, values, and expectations of the reader influence how he/she interprets meaning and understand the narrative report. Moreover, as Langer, (1991) explains, 'the reading process always involves viewing the text through a perspective that is continually on the move', (cited in Riessman (2008:p.115), suggesting that the interpretation of texts is relative, and not necessarily the final representation The section below discusses the method of research processes including the operationalisation of the above theoretical contexts.

3.3   Research Method: Narrative enquiry

Narrative enquiry is defined as a research orientation that directs the researcher's attention to narratives as a way in which to study an aspect of society. Narrative enquiry is about finding meaning in the stories which people use, tell, and even live (Ospina, 2005:p.144). Clandinin & Connelly 2000 (cited in Giovannoli (2000:p.5) define narrative enquiry as a way of understanding experience. Narrative enquiry is focused on the narratives and stories as they are told, implicitly and explicitly by individuals (Ospina, 2005:p.144).

The above narrative interpretive framework highlights the way in which primary experiences are represented by the researcher (the agency of the teller) who composes narratives through: listening, transcribing, analyzing in order and reading to understand the story which is being told. This is because narrative enquiry is participant led and case-centered the participant (the narrator) is the interpreter (Riessman 2008:p.11-13) of his/her experiences of medical help. The premises of narrative enquiry method applied in this

research are based on Riessman (2008) narrative analysis methodological rules. The method as one of the qualitative research approaches has its own unique analytical frameworks and features:

1. Giving emphasis on 'the told' – the events and cognitions to which spoken word refers to (the content).
2. Viewing language as a resource rather than a topic of enquiry and themes unmediated by researcher's prior theory - searching new theoretical insights from the data.
3. Keeping the story 'intact' for interpretive purposes. Attend to 'time' and 'places' of narrations and reject the idea of generic explanations.
4. Attending to the 'context' and detail contained in long sequences of stories.
5. Theorizing from a case rather than from components themes categories across cases (Riessman 2008:p.74)

Figure 8 provides a flow chart showing how the 'representation of experience' (theoretical contexts) is applied in the narrative enquiry process (research steps and procedures).

Figure 8   The Narrative Enquiry Research Flow Chart
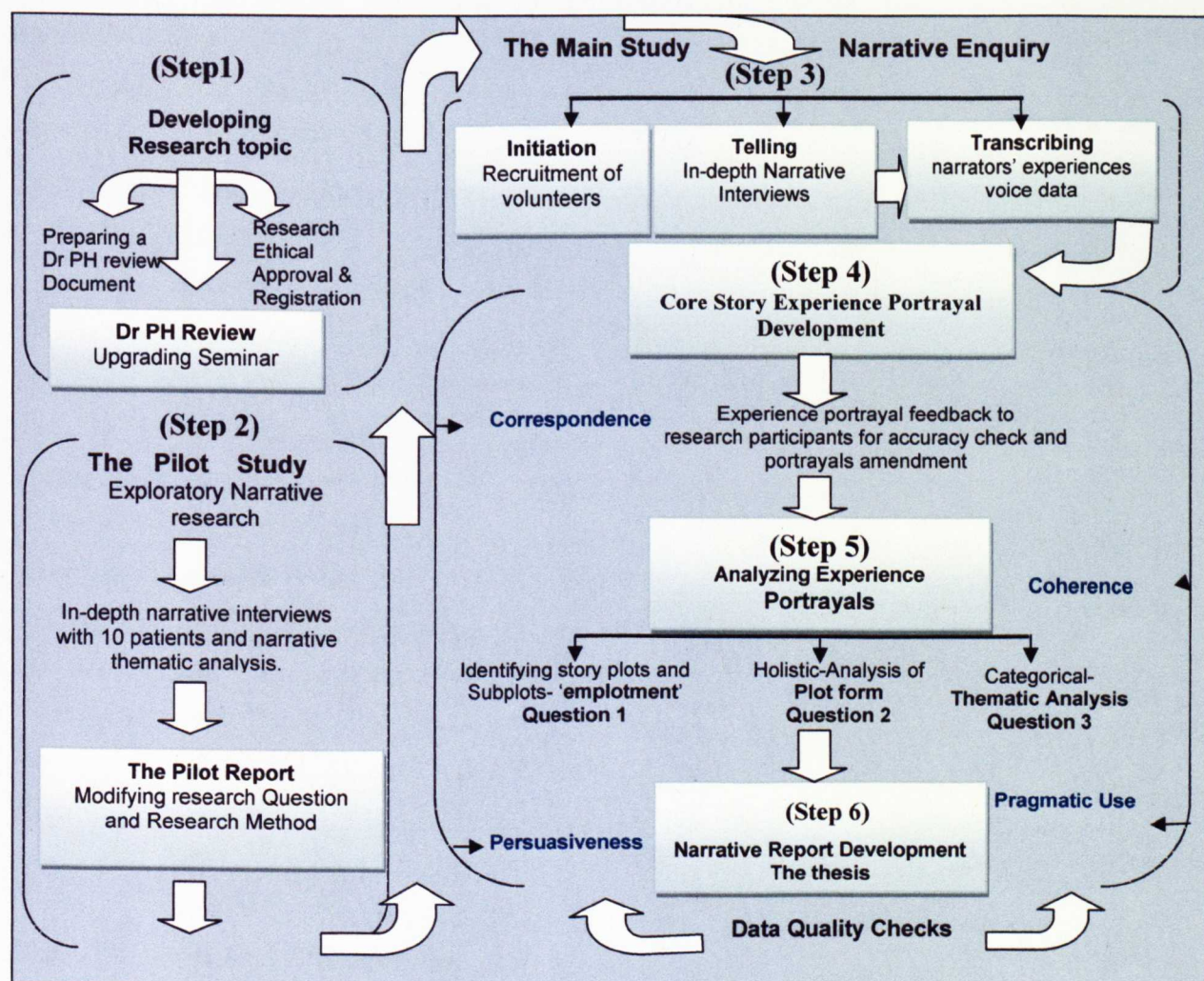
The figure above is a two part representation of the tasks undertaken in this research. Firstly, the preliminary research tasks briefly discussed earlier in this chapter were: **Step 1.** the ethical approval process; and **Step 2.** the pilot research and its outcomes: modifying

research question and research method (see report in Annex 2). The main field research involved: **Step 3.** recruitment of main study participants (initiation), narrative interviews (telling), and voice data conversion into text (transcribing); **Step 4** arranging verbatim transcripts and feedback to participants core story (experience portrayals development); **Step 5.** analysing experience portrayals (three phases of narrative analysis, each answering one specific question); and **Step 6.** preparing narrative report (this thesis). The above figure also shows the four key quality criteria, indicated in border line of the figure to represent how quality checks were ensured during the research, data analysis, and representation phases.

The section below discusses the operationalisation of research processes including the representation of patients' experiences. I will begin by discussing the initiation recruitment of subjects in preparation for the main field research, beginning from **Step 3** of the diagram in Figure 8.

3.3.1 Initiation: Recruitment of Participants

The pilot phase provided me with the advantage of being familiar with how the clinics operated the staff and the patients. Before proceeding into the main field research, in each hospital setting, face-to-face meetings were held with members of staff (chest physicians and TB nurses) in order to provide them with a verbal explanation about the purpose of the main research and the participant selection procedure. Information about the research was also provided to all of the clinicians and nurses in each clinic. I established a close rapport with the chest physicians and nurses, and discussed with them the type of volunteers which I needed in order to ensure the representativeness of the patient groups. My close discussions with clinicians continued throughout the recruitment process, and this involved offering reminders of the inclusion criteria and being sensitive to their busy clinical workloads and time constraints. In one chest clinic (Setting 2), however, the selection of volunteers was undertaken by the nurses separately from the routine weekly clinic setting. This was because, during the pilot phase, there was a lack of physical space for the interviews during the routine clinic hours (held on Mondays). Therefore, the interviews with the patients needed to be conducted on different days. At the start of the main research process, a face-to-face discussion was held with TB nurses who agreed to keep a folder containing information about the research and a message book in order to keep a record of the names and contact details of potential participants. In addition to this, I also received phone calls from staff passing on their messages in addition to my weekly visits to the clinic.

3.3.2 Study Participants

Thirty-two patients participated in the main part of this study. The participants came from diverse ethnic and social backgrounds, and were between 22 and 60 years of age, students

(n=7); unemployed (n=9) or employed (n=15). Almost all of the patients were residents of the three London boroughs except one (pt. 38), who was a resident of an outer London borough and was seeking treatment from the Setting 3 in London. Most of the patients were from the South Asian (n=17) and African (n=11) ethnic groups. Four patients (12.5%) were from other ethnic groups. Three patients were born in the UK: one Bengali female; one white British male and one Afro-Caribbean female. The remaining two patients were a male patient born in Portugal and a female patient born in Iraq. Two patients (pt. 18 and pt. 25) had lost mobility as a result of TB meningitis and were wheelchair bound at the time of interview. One of the patients (pt. 40) had pulmonary TB and also a glandular form of TB, and one other (pt. 42) was an ex-pulmonary TB case treated in 2001 and had TB of the bones. Table 3 presents the study participants' demographic characteristics, TB types and treatment centres.

Table 4   Characteristics of Main Study Participants

Participants	Female	Male	Total
Place of Birth			
Africa	7	3	10
South East Asia	7	10	17
UK	2	1	3
Others (Portugal & Iraq)	1	1	2
Type of TB			
Pulmonary TB	10	8	18
Non-pulmonary TB	7	8 ★	14
GP status			
Registered	17	13	30
Non Registered	-	2	2
Treatment Centre			
Setting 1	10	5	15
Setting 2	3	6	9
Setting 3	4 ✚	4	8
Non -English speaking	1	4	5
Age Group			
18-29	3	5	8
30-39	10	5	15
40-49	2	2	4
50-59	1	3	4
60+	1	-	1
Total	17	15	32
Keys: ✚ A patient resident in outer London area			
★ One patient with pulmonary and no-pulmonary TB			

Following their agreement to participate in the research, contact was established with the volunteers in two ways. On the one hand, in two research settings: 1 and 3 chest clinics, the referral process involved each volunteer being briefly introduced to me by clinicians, leading on to a further discussion about their participation in the study. On the other hand, in Setting 2, the contact details of each volunteer were left in the diary and all of the volunteers were subsequently contacted and arrangements made for their interviews. All of the interviews were conducted in rooms at the clinics, except one which was conducted at the participant's place of work. The recruitment of volunteers for interviews in a clinic

environment was not free from problems, particularly with regard to time. As the recruitment of participants was taking place after the patients had endured a lengthy waiting period before and during their medical consultations, their participation in research was a particular concern at the beginning of the study.

Despite this research concern, on the whole, there were only seven patients who were unable to participate due to a lack of time. However, this could be an underestimation, as there may also have been other patients who decided not to participate and whom I may not have been aware of. Of the seven patients who agreed to discuss the research with me, one felt ill and was unable to continue and the other six were unable to commit to the research because of time constraints. Recognising the participants' preferences was useful in terms of facilitating the context of the research interviews (Riessman, 1993). Before each volunteer was interviewed, they were given the option to be interviewed at home or in another venue of their choice. Amongst the 32 participants involved in this research, five were interviewed using interpreters. Two professional interpreters were booked for clinical consultations and were subsequently authorised by chest physicians to be involved in this research. The remaining three interpreters were bilingual hospital advocates from Newham General University Hospital Trust Interpreting Services. I recognise that the use of interpreters meant that the nature of the interpretive dialogue was obscured by their overt presence and there were concerns about the accuracy of their interpretations (Smith et al. 2008). Each interpreter's awareness of the research procedure and the importance of a word-for-word interpretation of *"what was said"* by *"the patient"* and *"the researcher"* was discussed and agreed upon by each interpreter prior to starting the interview with each participant. At the start of the interviews, I clarified my position as a student and an outsider – this created a relaxed environment in which the participants could talk freely and in which I was able to establish a good rapport and ensure their cooperation.

3.3.3 Telling about experience: Narrative Interviewing

The data collection phase included the initiation, the main narration and the questioning phase which was used in order to facilitate storytelling. I applied, Jovchelovitch and Bauer (2000) proposed rules for narrative interviewing. The initiation of the interview began with one open-ended question regarding patients' memories of events that they had experienced with regard to the phenomenon of acquiring medical help for TB, i.e. by asking the interviewee to reflect on his/her story and experiences of the pathways to diagnosis and treatment.

" Please tell me about your experience of medical help for your current illness. "

After the opening question was asked, no interruption was made until the informant signalled that they had reached the end (coda) (Jovchelovitch and Bauer, 2000). The next question I asked was intended to invite the interviewee to provide an extended account of his/her story, e.g. 'What happened next?' Sometimes, I posed a question relating to the exact wording or expressions of the participant. Further questions involved asking for specific examples or repeating key themes (metaphors) and repeated expressions and asking the interviewee to clarify the time or place of an event.

The aim was to gain thorough descriptions of their experiences of their paths to diagnosis and treatment through their recollection of their experiences of medical help (research phenomenon). This helped each interviewee to explore the description of his/her experiences in greater depth with minimal interference. However, some questions did emerge naturally with each interviewee; issues, for example, in relation to their family, work or studies. The interviewees were not coerced to bring up a new issue that had not featured in their story, and they were not interrogated or questioned as to why they had told their story in such a way (Jovchelovitch and Bauer, 2000). The process of case-centred in-depth interviewing meant that I was required to remain flexible and sensitive to the differences that existed between each individual's style of narrative construction. My participants differed in many ways, and each had a unique way of organising their story. Some of the participants told their stories almost as if they were symbolic of narrative, starting at the beginning, progressing to the middle and moving to the end, starting in the past and moving to the present. Others went through the intimate details of the events they had experienced, and others started from their initial experience of their illness and moved quickly onto their more recent and current experiences of medical help. However, it was my task as a researcher in the questioning phase to ask the participants to help me to understand their journeys through their stories in order to understand the chronology of the events by paying attention to the places and times of their experiences.

In spite of these challenges, there were similarities between most of the interviewees in terms of remembering specific dates of their previous healthcare encounters. However, all of the interviewees, as they began to structure their stories, went back and forth in order to remember specific months by using either the beginning, middle or the end of calendar months in order to be more specific about the time of events. Almost all of the patients had a good recollection of the start date of their treatment, their hospital admission and discharge and the length of time taken while seeking care from their GPs and for specific tests. Most were able to use this to help them to recall the months of earlier consultations with their GPs, WCs and the A&E departments. In Annex 3, p.240, I have provided the Aide Memoire used in the narrative interviews. It contains my initial open-ended question and prompts and clarifying questions asked of interviewees in the construction of their stories.

3.3.4 Transcribing Experience

The process of transcribing the narratives started immediately after each interview. I began the process by listening to digital voice recordings (OLYMPUS WS-311M) in order to familiarise myself with the voice data, particularly the participants' speech and ways of expressions including difficult words, by locating specific issues and cross-checking with the notes I had taken during the interviews. The voice data were then transported into NVivo8 for transcription. Performing transcription using the NVivo8 software was useful due to its voice speed control and ability to go back and forth through the data during the transcription process. Being able to transcribe all of the interviews myself I had the advantage of ensuring the quality of the data recording. However, the process was painstaking, laborious and time-consuming, as it involved over 600 pages of transcripts.

During the transcription of the voice data, I adopted Riessman's suggestion of keeping the original full transcripts of the interviews, containing all of the pauses, emotions and utterances (1993). These details of these narrative transcripts are useful for understanding the narrative construction process in the storytelling context, revealing how a personal narrative is social at many levels and how, at the local level, it is composed of jointly-crafted collaborative conversational interaction (Riessman, 2008: p.30-6). In hindsight, I also wanted to avoid the need to return to the original voice data if any particular issue of theoretical insight arose during the analysis of the textual data. The conversational style of the narrative transcripts was centred on the participants' construction of their stories, including my interruptions. In some instances in which I asked the participants to relate the events in chronological order, elements of the stories told by the participants were unavoidably repeated and needed to be integrated and arranged sequentially from the beginning to the end of the story-line when arranging the transcripts.

In this research narrative interviews and data transcription were undertaken over a period of six to eight months. This included follow-up contact with each participant in order to check the accuracy of the data, the core story experience portrayals were sent to participants and made contacts to receive feedback. This extended contact with the participants gave them time to reflect on their stories and the opportunity to make comments on their experience portraits. Some participants also discussed their views with me in their follow-up clinic sessions and on the telephone.

i.   Arranging experience data for analysis

Following the complete conversion of Narrators' Voice data into verbatim transcripts, the decision on how to arrange data, what to include and how to display was based on the thesis

research questions. A further modification was made to the narrators' verbatim transcripts before beginning the analysis process. The first step, undertaken was data reduction and elimination process in order to determine the experience that is essential to the research questions (see point 1 and 2 from the list below). The second step was developing core story portrayal and feedback to research participants (in point 3 and 4 below). The reduction of original transcripts into core story experience portrayals was achieved as follows:

1. Deleting my utterances from the textual information (Emden, 1988).
2. I applied Gee's approach of arranging the transcripts along the line of speech units; a single sequence of words comprised an 'idea unit', and units with similar content formed 'stanzas', called thematic points. This was done in order to arrange narratives as if they had emerged full blown from the narrators" (Riessman, 2008:p.93). (see Annex 2, p.240-1)
3. Going through the text and identifying texts that could be reduced or eliminated and identifying invariant constituents of the patients' experiences contained in plots and subplots that captured the core story; (Emden, 1998).
4. The rearranged story was a core story, meaning that it was a succinct portrait of the patient's experiences. This portrait was sent to each participant for feedback, (Emden, 1998) accompanied with a letter explaining what to do, a copy of the full transcript and a transcription quality check form. Each participant was asked to read the summary portrait (core story) and to comment on its accuracy and return it in the pre-addressed envelope (see Annex 3, p.242 and Annex 4, p.251-5)
5. The analysis of the text was then limited to the core story in order to identify 'plots' and 'subplots'; (Emden, 1998). (see Annex 4, p.255)
6. The experience portraits were then read for global impressions, with each narrative considered as a whole. Understanding the whole narrative was necessary in order to understand its parts, with sections interpreted in the context of the others (Lieblich et al. 1998). I then looked into the 'plot types' in order to identify how the storyteller understood his/her actions and their meaning, which characterised the plot types or forms used by the teller; (Lieblich et al. 1998; Riessman, 1993).
7. In the final step of analysis, I looked into the content of each plotline in order to generate categories of medical help. I then looked into each 'subplot' for specific themes in order to arrange the themes according to the categories of medical help, leading to a categorical thematic analysis of the participants' experiences.

3.3.5 Analyzing Experience

This section will begin with a description of the major aim of my choice of narrative analysis techniques in the investigation of the thirty-two participants' experiences. The analysis of participants' experiences (as stated in point 5 to 7 above) were achieved in three parts and each part sought to answer one specific research question in three separate chapters (as indicated in brackets). The first research question involved the analysis of what had been said, looking for 'referential meaning' in the narratives. The second question needed analysing how it was told necessitated an examination of the narrators' forms of expression of 'interpersonal meaning'. The third question achieved by analysing how the narrators connected their experiences required an examination of what they had said specifically in terms of 'textual meaning'. My choice of analysis method was based on the need to conduct a more descriptive and explanatory narrative analysis in order to capture narrative content and forms: 'what was told' and 'how it was told' by the participants (Polkinghorne, 1988; Sandeleowski, 1991). These lend to different forms of analysis that relate to each of the

thesis three research questions. A brief outline of the three stages presented about three separate Chapters of results and analysis of narrative data. Fig 9 below illustrates the steps which I employed in the analysis of narrative data.

Figure 9   Steps for Analysis of Participants' Experience
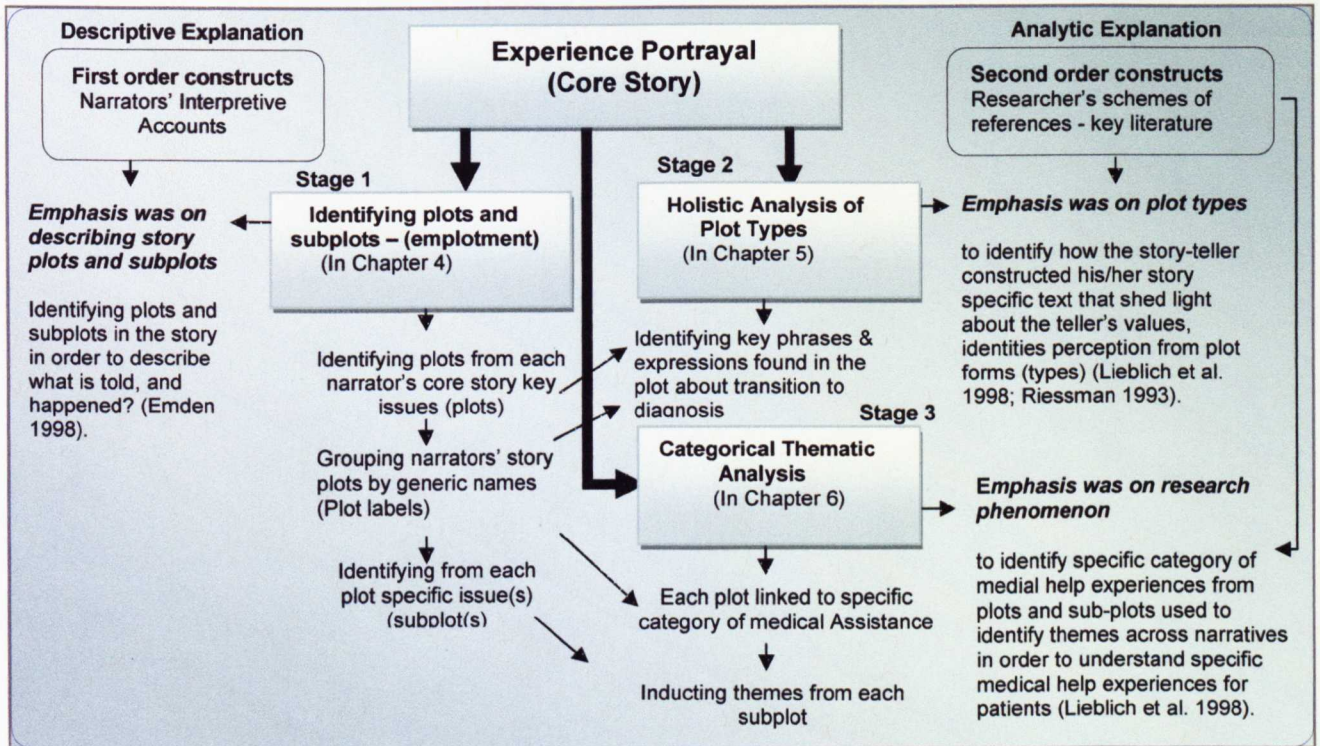
i.   Stage 1 (In chapter 4)

Q1: What did the patients say about their pathways to TB diagnosis and treatment?

The aim of this analysis was to understand what the research participants did say about their experiences from their descriptions of events. In the analysis of 'what was told by the narrators', I applied a descriptive analysis method proposed by Emden (1998) in the form of an analysis of the basic outline of events and the perspective of the teller in what they said. This process involved identifying key story plots and subplots, which were integrated together in order to create a cohesive story or set of stories. Emden proposes some key steps for developing core stories for analysis. (see point 1-5, in p.69 above) The development of experience portrayals (core story creation) was based on Emden's (1998) proposed guidelines for narrative analysis of verbatim transcripts. In the process of core story creation (experience portraits), I needed to go through the participants' transcripts and select key textual data that were relevant to the research question, with an emphasis on the time, context and content of each participant's experiences from his/her stories. (see Fig 9 above)

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ii. Stage 2 (In chapter 5)

Q2: How do patients tell the story of their experiences of pathways to the diagnosis?

The aim of this analysis was to understand the perspectives of research participants in order to reinterpret their experiences as close to their interpretations. In my analysis of 'how the story was told', I employed a more comprehensive method proposed by Lieblich et al. (1998) in order to examine individuals' stories in terms of their holistic forms. Holistic Form Analysis is a method applied for the interpretation of each participant's experience in terms of a global impression and narrative typology (Lieblich et al. 1998). According to Lieblich et al. narratives are told in various forms or narrative typologies. The favoured narrative typologies are: *tragedy; comedy; romance and satire* (p.88). This view is reflected by Riessman, who also maintains that "Narrativisation tells not only about past actions, but how individuals understand those actions, that is, meaning... plots vary in type: [see the four typologies above]. Tellers pour their ordinary lives into these archetypal forms."(Riessman, 1993:p.19). During the analysis, I used the participants' core stories and the plots I have described in stage one of the analysis. The question which I asked myself was: how can I identify the narrators' forms of storytelling in order to create a holistic understanding and representation of the tellers' experiences?

In this step, I began my analysis with an attempt to understand each participant's story as a whole in order to gain a global impression (Lieblich et al. 1988). The main assumption of the holistic form analytical model is that "the formal aspects of structure, as much as content, express the identity, perceptions and values of the storyteller" Lieblich et al. 1998:p.88). This implies that each narrator's form of storytelling is important for my understanding and interpretation of their perspective. This is because the participants' forms of storytelling, "narrative plot types [forms]" by each narrator, the terms of which he/she wants to be interpreted' (Riessman, 1993:p.19). I considered narrative form analysis to be a useful way to learn from the narrators' experiences in order to understand the commonalities and differences between the participants' experiences from their interpretations and forms of storytelling.

By looking into the patients' forms of expression and meaning contained in the story plot about the transition to diagnosis from each narrator's account, I was able to observe five different forms of expression that revealed each narrator's actions and the meaning conveyed in the plot of their story. (see Fig 9 above) The pattern of behaviour, actions, phrases and metaphors used in the narratives helped me to group narrators' by their five different types of action in relation to medical help: accepter (accepting medical help provided); tolerant (tolerating inadequate medical help provided); doubter (doubting medical

help); coercer (Applying pressure for referral) and sufferer (suffering a great deal before being referred). The process of 'plot types' induction from the data is discussed in Chapter Five more fully. This form analysis has provided me with insights into the level of meaning of the participants' actions from their plot and allowed me to identify commonalities and differences between their stories.

In her case study of mature women's experiences of returning to education, Hazel Wright conducted a holistic form analysis of her interviews. Wright was able to develop typologies based on the characteristics of behaviours found in the narrative material, rather than using the favoured four narrative typologies described above, (2009:p.62-73). I used a similar approach in order to identify narrative typologies derived from plot types and the forms of the narrators' expressions, (Riessman, 1993; Lieblich et al. 1998) for the reason that the plots types found in the narrators' expressions did not sufficiently match the four common narrative typologies mentioned by Riessman (1993) and Lieblich et al. (1998).

iii. Stage 3 (In chapter 6)

Q3: What did patients say specifically about their experiences of medical help?

The aim of this analysis was to go more in depth in the analysis of the data in order to identify more specific issues contained in the research participants' descriptions about their experiences of medical help from professionals. This final stage of analysis was based on Lieblich et al.'s categorical content (thematic) approach to narrative analysis. This analysis involves "a selection of subtext... on the basis of a research question...' (Lieblich et al.1998: p.112).

The categorical thematic analysis was based on the plots and subplots of each core story presented in the first stage of the analysis. In this section of the analysis, I looked into the temporality of the core story plots and subplots, paying attention to the times and locations of experiences. In doing so, it became clear that the pathways to diagnosis and treatment broadly involved three stages in a continuum: '*before diagnosis*'; '*during diagnosis*' and '*after diagnosis, including treatment*'. Using these stages of analysis helped me to arrange the plots and subplots in a sequence, by linking them to the times and places of the participants' experiences.

I examined the categories of medical help which each plot referred to and found specific themes within subplots. (see Fig 9 above) These data were arranged according to each category of medical help for the different groups of narrators. I used a line-by-line technique in order to identify the key themes of subplots in order to understand 'the content universe' (which I took to mean the experience of the phenomenon in question).

3.2.5.1 Summary of Research Analytic Framework

In this section, I discussed the three steps of analysis and also indicated in Fig 9, the processes which were applied in analysis. In summary, the three stages of analysis were carried out in three chapters in order to answer the broad and specific research questions: (1) the analysis of what had been said involved looking for 'referential meaning' in the narratives; (2) analysing how it was told necessitated an examination of the narrators' forms of expression of 'interpersonal meaning'; (3) analysing how the narrators connected their experiences required an examination of what they had said specifically in terms of 'textual meaning'. Each level of analysis reinforced the others in the interpretation of the participants' experiences in a step-by-step process in order to make the analysis process transparent for readers.

Emden's method was chosen as it places the emphasis on arranging stories around patients' experiences and 'member checking' of transcripts by participants to ensure the accuracy of the data. Lieblich et al.'s (1998) analytic techniques extended the analysis beyond the descriptive in an attempt to understand patients' stories by employing multidimensional approaches.

3.4 Narrative enquiry: strengths, weaknesses and challenges

It is known that each research method has inherent strengths and weaknesses and each methodology also has its own inherent limitations, (IUPS, 2004: p.10) and in this section these issues are discussed. The primary justification for using narrative enquiry in this research was based on the research questions have sought to understand participants' experiences of access to diagnosis and treatment. As Hyden points out, "Illness narrative' gives voice to suffering in a way that lies outside the domain of the biomedical voice... has been one of the research methods chosen for use with biomedicine, illness and suffering.", (Hyden, 1997: p.49). Despite its strengths, storytelling as an object of study (methodological tool) in research has its challenges and limitations with regard to the analysis of experiential evidence. In this section, I want to provide a brief outline of these limitations and challenges, before proceeding on to the next section of this thesis.

As Hurwitz et al. (2004) point out, 'the deep contextualization, fluidity and ambiguity of narratives, embedded as they are in the flux of everyday life, challenge the neatness of the concept' (p.228). Each narrative depicts only one version of what a story is about (what has been experienced), as interpreted by the teller. It is, therefore, limited in the sense that it does not provide a sufficient basis from which to form an alternative view of the context and

content of the experiential evidence. Furthermore, each narrator has a unique way of telling the story of what he/she has experienced and his/her ability to reflect on the finite details of the contexts of his/her experiences. This is important because it will result in the asymmetry of narrative constructions between stories and the challenges of narrative representation and evaluation. Earlier I noted that, in two research settings, the narrative interviews were conducted in a clinic setting during the patients' follow-up treatment. The patients were given the option to reschedule their interviews, but most had decided to continue with the first point of contact. Time was a challenge to some extent, which may have compromised the narrators' ability to construct their stories as fully as possible.

Moreover, as Hurwitz et al. (2004) point out, there is a distinction between 'narrative truth' and 'historical truth'. There are complex and dynamic interactions between these two concepts (p.219). The evidential material contained in this thesis is a form of narrative truth, and only one of the many ways of seeing things (Crotty 1998), via the perspectives of patients at a given point in their reflection on the events they had experienced. According to the authors above, historical truth about any event that has been experienced does not exist without a reason. This implies that narratives have limitations in terms of their being credible evidence, unless backed by supportive evidence from other research. Connections have to be made between what is narrative and what is historical in the interpretation of research findings. Furthermore, in reading a narrative representation, the interpretation of this narrative report is limited. I agree with the point made by Lieblich et al. (1998) that narrative material may only appeal to particular groups of audiences whose values, judgments and understandings match those of the material.

Every reader also has his/her own way of viewing research phenomena, largely determined by his/her culture, language, values, philosophy and social position. Each of these factors, in one way or another, influences his/her interpretations. As discussed earlier, the thesis constructionist lens assumes that there are multiple constructed realities and this research explores the experiences of patients within their context of medical assistance that is changing. The narrative enquiry within the qualitative interpretive paradigm does not seek to produce generalisable results. The similarities and commonalities of pathways to diagnosis and treatment and the participants' experiences of medical help found in this research may signify the transferability of these findings to similar population groups in London. However, the changing nature of TB services (the context), particularly in the NHS in recent years, may present limitations when making any assumption regarding the applicability of these findings to any given context. This is also determined by the reader's assessment of the findings in relation to other areas. I will reflect on these issues particularly applying the method in research with the participants of this study in greater depth in the final chapter of this thesis. In the section that follows, I will discuss how this method

addresses key quality criteria to ensure 'rigour' in the representation of participants' experiences in this research.

3.5 Evaluating narrative representation in narrative analysis

Riessman proposes four key criteria for evaluating narrative research and story representation within an interpretive paradigm. These criteria of narrative representation should address the issues of: *persuasiveness; correspondence; coherence* and *pragmatic use* (1993: p.68). I will consider how this thesis addresses these criteria in the following section.

3.5.1 Persuasiveness

The criterion of persuasiveness refers to the plausibility of the interpretation of patients' experiences. Riessman has noted that the persuasiveness of narrative representation is best demonstrated when theoretical claims are supported with evidence from research data and when alternative explanations are taken into account (1993:p.65). In the analysis of narrative interviews, a range of strategies for data analysis were employed in order to examine the participants' accounts, drawing upon models of doctor-patient communication in order to generate alternative interpretations of the data. Persuasiveness also refers to the representation of the report, particularly the interpretation of a narrative text. Throughout this thesis, I have retained the voices of the research participants and their evidence in the analysis of their descriptive explanatory accounts *(first order constructs).* In the holistic and thematic analysis process, I ensured that the *'second order constructs'* (theoretical claims) were supported with evidence from the participants' first order constructs. (see Fig 9, p.70) The experience portrayals were clearly presented in order to demonstrate the persuasiveness of narrative representation by providing details (where possible) of the participants' words in order to let them speak for themselves.

3.5.2 Correspondence

The second criterion is correspondence. Lincoln & Guba (1994) have suggested checking data with those participants and co-constructors of the story who produced the data. This implies that going back to the participants and clarifying issues that emerge during the interpretation phase will ensure rigorous data analysis. During the interviews, each participant was asked for his/her consent to further contact in order to check the transcribed

interview record for accuracy and to attain his/her reflections on events in his/her personal narrative. Almost all of the participants agreed to my request. As previously stated, succinct experience portraits and the full versions of the interview transcripts were sent to each participant so that they could assess the accuracy of the core story and comment upon on their stories. With regard to the truthfulness of the interpretive work, the emphasis in this thesis is on obtaining 'an accurate representation of the fact of the matter [and] verification of the precise and accurate reflections in the story by the participants themselves' (Riessman, 1993). My view is that, as a general rule, obtaining feedback from participants on their experience portraits included in this thesis should meet this criterion and indicates the authenticity of this research. Moreover, returning stories to the narrators after a period of reflection and obtaining the participants' responses proved to be useful in learning how the participants' viewed the representation of their experiences in the condensed core stories.

3.5.3 Coherence

The criterion of ensuring coherence refers to narrative interpretations that are more than ad-hoc and goal-orientated (Riessman 1993: p.67). This thesis contains sufficient material on methodological and data analysis strategies that are not ad-hoc and that were used to answer specific research questions. In this thesis, the issue of coherence encompassed three types of coherence: global (the global impression of the interviewee's account); thematic coherence (themes identified in the content of the stories told); and temporality coherence (the order of events and actions presented by interviewees), Agar & Hobbs, 1982 – (cited in Riessman, 1993:p.67). These levels of interpretation are based on the co-construction of stories with participants, which both supported and enhanced the authenticity of the stories (Lincoln & Guba, 1985). This was achieved by including the participants' core stories as if they were full-blown autobiographical stories from 'self' stories' and allowing them to speak for themselves Gee, 1986 – (cited in Riessman, 2008:p.35). The findings included transparent data from the core stories and extract which highlighted plots and themes in order to strengthen the soundness and coherence of the data representation. Finally, the transferability of research findings to other settings has been proposed as an important indicator of quality in qualitative research (Hammersley, 1992). This thesis contains sufficient material to fully describe the context, meaning that readers can judge the applicability of the research findings to their own or other contexts for themselves (Seale 1999).

3.5.4 Pragmatic adequacy

The criterion of pragmatic adequacy refers to the extent to which the study becomes the basis for the work of others (Riessman, 1993). The theoretical framework and narrative analytical frameworks used in this study meet this requirement. Narrative representation based on storytelling and the application of a systematic approach by participants in order to generate empirical data could be applied to elicit other TB patients' experiences of their pathways to diagnosis and treatment and, more specifically, the medical help they have received from their health care providers. The notion of consistency between the purpose of the research, the methodology used to collect and analyse data and the philosophical assumptions of the research paradigm; (Crotty, 1998) has been addressed in this chapter. A prolonged engagement with the research participants and repeated interactions can ensure that the data collection process is rigorous (Lincoln & Denzin, 1994).

The experience portrayals were checked for accuracy with participants and comments were used to develop core story portrayals. It is expected that these enhance the rigour and trustworthiness of the research findings. In this thesis, a clear description of how interpretations were formed; the visibility of all accounts; specifying how the successive transformation of data was accomplished; (Riessman, 1993:p.68) and including all of the original primary data in the report and as supplementary references.

The next three chapters will present the analysis and results of participants' experiences in more detail and each part sought to answer one specific research question. Chapter 4 will begin with a preliminary analysis of participants' stories.

Chapter Four: Analysis of core story plots and subplots

4. Introduction

This chapter will attempt to provide answers to the first research question posed. Preliminary results and analyses of participants' experiences of illness, along with chronology of healthcare contacts and time taken by the patients and providers, are detailed. The processes of experience portrayal (core story) development are explained. A descriptive narrative analysis based on core story 'plots' and 'subplots' are presented. Finally, the results and analyses from this chapter are summarised with reference to the research question.

As noted above, the first research question is specifically related to deriving meaning from story plots, or 'what was told' by the narrators. The aim in this chapter is to reveal meaning from core issues/events contained in narrative of core story experience portrayals to provide answers to the research question.

4.1   Results of participants' chronology of healthcare contact

This section presents the results from preliminary analysis of narratives texts for chronology of events, paying particular attention to each participant's description of time taken from first illness manifestation to first healthcare contact, and diagnosis and treatment.

Table 5 contains relevant data for each patient. Each patient's first awareness of TB symptoms; the time and place of first healthcare contact, the date of their diagnosis, and lastly the date they began TB treatment. Patients' pathways to healthcare involve either GPs, walk-in centres, or an A&E department, and the treatment phase also involve chest clinics for all participants in this research. (see Table 5 below).

4.1.1 Analysis of time of participants' healthcare contact

The literature review in chapter 2 highlights the usefulness of mapping out and identifying barriers along the continuum of patients' pathways to diagnosis and treatment. As a preliminary analysis, I constructed a table, noting down chronology of events and dates of contact from stories. Arranging data in such a way and looking the chronology of events in terms of time and place of the patients' medical experiences is a useful way of analysing the delay caused either by the patient or by providers of TB services, as well as being useful for the subsequent arrangement of transcripts sequentially.

Table 5 **Participants' characteristics and healthcare contacts.**

Patient (ID)	11 (WS30011)	12(WS30012)	13(WS30013)	14(WS30014)	15(WS30015)	16(WS30016)	17(WS30017)	18(WS30018)	19 (WS30019)	20(WS30020)
Age	42	29	29	35	30	30	50	26	34	26
Sex	F	F	F	F	M	F	M	M (on wheel chair)	F (NES)	F
Birth place	UK (Afro Caribbean)	Somalia	India	India	India	India	UK -(White homeless)	India	Somalia	Nigeria
Occupation	Student	Un employed	Waitress	Food Factory worker	IT programmer	IT consultant	Unemployed	Fashion industry	Unemployed	Student
Known TB contact and place	Not Known	A neighbour and friend in Somalia	Not Known	Not Known	Not known	Not known	Not Known	Not Known	Cousin had Spinal TB	Not known
Type of TB	Spinal TB	PTb	Glandular Tb	PTb	Glandular TB	PTb	PTb	TB Meningitis	PTb	Pneumonia – PTb
Triggers to seek medical help	Small lump on my back, very painful and restricting my ability to function. (+++)	I started to cough, lost weight, sweating at night, cannot breath and feeling tired (++++)	I noticed swelling on my right elbow, very painful, cannot work, and do anything on my hand I took pain killers & herbal medicine for a month (+++)	Dry cough, fever and weakness (++)	Noticed swelling on neck and did not do anything for two weeks (+)	In July coughing thought it was caused by painting work in house went to GP after one week (++)	I had sever flu like symptoms, coughing phlegm it was getting worse in Jan I tried to register with a GP (++)	I felt numbness on my left hand and then while I was in A&E I felt weakness and loss of sensation on the left side of my body.	Feeling cold and started to cough a lot (+++)	I had sharp chest pain and unable to breath and struggling for air I then went to WC (++)
First health care contact	GP	GP	GP then self referred to A&E	GP	GP	GP	GP then A&E	A&E	GP	Walk-in Centre
1st symptoms of TB	May, 2008	Dec, 2008	>Jun, 2008	May, 2009	End of July 2009	July, 2009	Jan, 2009	Jun, 2009	Mar, 2009	Apr, 2009
Health care contact	May, 2008	Dec, 2008	Jul, 2008	End of Apr, 2009	Aug, 2009	Aug, 2009	GP in Jan & A&E Mar, 2009	May, 2009	Mar, 2009	Apr, 2009
Month of TB Diagnosis	Mar, 2009 Blood tests, X-ray, Lumpectomy of fluids; CT scan and skin tests	Jun, 2009 -ve diagnostic tests results Symptomatic diagnosis	Aug, 2009 X-ray CT scan Monteux Test	Jul, 2009 Patient request for chest X-ray.	Oct, 2009 X-ray, blood test; Ultrasound	Aug, 2009 X-ray, blood test; Bronchoscope. Test	Aug, 2009 X-ray (St Thomas' Blood test	Jun, 2009 MRI	Apr, 2009 X-ray	Oct, 2009 No firm diagnosis as yet, she had X-ray, blood tests, and Pleural sample cultures
Start of TB Treatment	Mar, 2009	6th Jun, 2009	Aug, 2009	Aug, 2009	1st Nov, 2009	Sept 2009	Aug, 2009	25th Jun, 2009	Apr, 2009	Oct, 2009

Glossary Keys: ID : Anonymized participant's voice data   PTb = Pulmonary TB   Known TB signs   + = represents a symptom typical of TB signs
NES = non English speaking

Table 5 Participants' characteristics and healthcare contacts

Patient (ID)	21(WS30021)	22(WS30022)	23(WS30023)	24(WS30024)	25(WS30025)	26(WS30026)	27(WS30027)	28(WS30028)	29(WS30029)	30(WS30030)	31(WS30031)
Age	26	54	24	33	53	30	32	?	22	34	?
Sex	M	M (NES)	M	F	F (on wheel chair)	M	F	M	M	F	F
Occupation	Student	Unemployed	Factory worker	Nursery Nurse	House wife	Student	Student	Banker	Food processor	Student	Student
Birth place	India	Somalia	Portugal	Nepal	Kenya	Somalia	India	India	Sri Lanka	Pakistan	Ghana
Known previous contact with TB and place	Not known	in Somalia	At work in a factory in London	Not known	Not known	A distant relative in Somalia	Lives with a family member PTb case	Not known	A close friend relatives in SL	Not known	Not known
Type of TB	PTb	Spinal TB	PTb	Skin TB	TB meningitis	PTb	PTb	Glandular TB	PTb (Pneumonial)	TB meningitis	PTb
Triggers to seek medical help	I was coughing for about a month at night time I could not sleep well (+++)	I had a painful back fourteen months ago I went to see my GP. (+)	It all started to cough a lot cough with phlegm coming out. (+++)	Had a pain in my two fingers after about a month the pain restrict my hand and became unbearable.	I fell down by accident and had a severe headache after that my husband took me to the A&E	I had a dry cough, sweating at night cannot sleep at night lost weight (+++)	I started to cough, feeling cold, cannot eat and had a fever. (+++)	I noticed a small swelling on my neck soon the swelling got bigger I needed to see a GP. (++)	I started to cough feeling tired cannot breath and had a chest pain (++)	I started to feel tired, losing weight, had a temperature and vomiting blood as well (I thought it was stress from work)(++)	I was coughing and sweating, my throats were hurting. (++++)
Time of first TB Symptoms	Apr, 2009	Sep, 2008	1^{s}Jun, 2009	Nov, 2008	Feb, 2009	Aug, 2009	May, 2009	Jun, 2009	Nov, 2009)	Apr, 2009	Apr, 2009
First Healthcare contact	Walk-in Centre	GP	GP	GP	A&E	GP	GP	GP	GP	GP	GP
Month of Health-care contact	Apr, 2009	May, 2008	May, 2009	Dec, 2008	Feb, 2009	Sep, 2009	Jun, 2009	15th Jun, 2009	Nov, 2009	Jun, 2009	Apr, 2009
Month of TB Diagnosis	Aug, 2009	Apr, 2009	Jul, 2009	Apr, 2009	Feb, 2009	Nov, 2009	24th Jun, 2009	15h Aug, 2009	Nov, 2009	Aug, 2009	Oct, 2009
Start of TB Treatment	Aug, 2009	Jul, 2009	Aug, 2009	4th Apr, 2009	Feb, 2009	6th Nov, 2009	26th Jun, 2009	15 Aug, 2009	Nov, 2009	Aug, 2009	Oct, 2009

Glossary Keys: PTb = Pulmonary TB   Known TB symptoms: + = represents a symptom typical of TB signs
NES = non English speaking

Table 5 Participants' characteristics and healthcare contacts.

Patient (ID)	32(WS30032)	33(WS30033)	34(WS30034)	35(WS30035)	36(WS36)	37(WS30)	38(WS30038)	39(WS30039)	40(WS30040)	41(WS30041)	42(WS30042)
Age	42	31	35	35	34	50	37	60	44 (NES)	22 (NES)	47 (NES)
Sex	F	F	M	M	F	M	F	F	M	M	M
Occupation	Unemployed	Care Assistant	Construction	Chef	Nurse	Unemployed	House wife	Retired	Chef	Shop assistant	Labourer
Birth place	Somalia	Ghana	Pakistan	India	Kenya	Nigerian	UK (Bengali)	Iraq	Bangladesh	Bangladesh	India
Known TB contact	Not known	Not known	Not known	Not known	Sister Kenya	Not Known	Not Known	Not known	Not known	Not known	Sister in-Law in London
Type of TB	Spinal TB	PTb	Glandular	PTb	PTb	PTb	Ptb	Ptb	Abdominal TB	PTb & Gland Tb	Bone TB X-pulmonary TB case in 1991 had full treatment.
Triggers to seek medical help	Back pain, losing weight, had a temperature at night shivering as well. I had all signs of TB symptoms (+++)	II had a dry persistent cough, itching throat and temperatures. (++++)	I had swelling on my neck and felt unwell, lost weight the pain in my neck was small (+++)	I started to have a dry cough, chest pain, vomiting, lost weight also sweating (+++)	I started to cough green & yellowish phlegm. I took cough syrups antibiotics for a month and a half (++++)	I started to have chest pain, sweating coughing with some blood lost weight me (+++)	I started with severe cold and cough with phlegm for a month I took paracetamol and not getting better (++++)	I started to cough vomiting lost about 20 KGs cough with phlegm like a gray ball & had a fever (+++++)	I had pain on my left side of my stomach I The pain abdominal pain started since over a year ago (+++)	I started cough and, sweting at night and losing weight, swelling on my neck and my nose was bleeding as well. (+++)	I had pain on my knee started in January 2008. I used to go to GP every week
Time of first TB Symptoms	Dec, 2008	Jun, 2009	Jan, 2009	May, 2009	Jun, 20 09	Oct, 2008	Apr, 2008	Nov, 2008	Mild abdominal pain > a year ago	Jun, 2009	Jan, 2008
Firs Health Care contact	GP	Walk-in Centre	GP	A&E	GP	GP	GP	GP	GP	GP	GP
Health-care contact	Jan, 2009	July, 2009	Jan, 2009	13th May 2009	July, 2009	Oct, 2008	May 2008	Nov 2008	Oct, 2008	June 2009	Since 2008 for non TB specific symptoms
Month of TB Diagnosis and tests given.	Apr, 2009 In Africa – MRI, X-ray and Spinal aspiration to drain abscess for culture	Aug, 2009 X-ray; blood test, CT scan	May, 2009 Lumpectomy, chest X-ray, blood tests	May, 2009 X-ray Blood test Pleural Aspiration	Aug, 2009 X-ray Blood test	Feb, 2009 X-ray, Blood test Sputum test Bronchoscope	Nov, 2009 X-ray, Blood tests, Sputum Test	Nov, 2009 X-ray Blood tests Sputum tests	13th Jan, 2009	Aug, 2009	Had surgery on knee and received several tests and RX as in patient only for six weeks
Start of TB Treatment	Apr, 2009 (Tanzania)	18th Aug, 2009	May, 2009	May, 2009	Aug, 2009	Mar, 2009	Nov, 2009	Nov, 2009	13th Jan, 2009	Aug, 2009	Dec, 2009

Glossary Keys: PTb = Pulmonary TB   Known TB symptoms: + = represents a symptom typical of TB signs
NES = non English speaking

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The table 5 shows a general delay between the onset of symptoms and the point when the patient contacted a healthcare professional, ranging from within a week (pts.19 and 41) to six weeks (pts.36 and 30). The majority of patients sought healthcare within a month of experiencing illness. The table also showed a delay which was associated with care providers. These delays ranged between one and three months, and were reported by 13 patients (pts. 16, 15, 18, 19, 23, 25, 26, 27, 28, 29, 30, 35 and 41). Delays between three and 14 months were reported by 19 patients (pts. 11, 12, 13, 14, 17, 20, 21, 22, 24, 31, 32, 33, 34, 36, 37, 38, 39, 40 and 42). Figure 10 is a graphical illustration showing the participants' pathways to diagnosis and treatment. The diagram refers to the length of time in months for first contact, referral, diagnosis and treatment.

Figure 10   Time taken to obtain diagnosis and TB treatment by participants
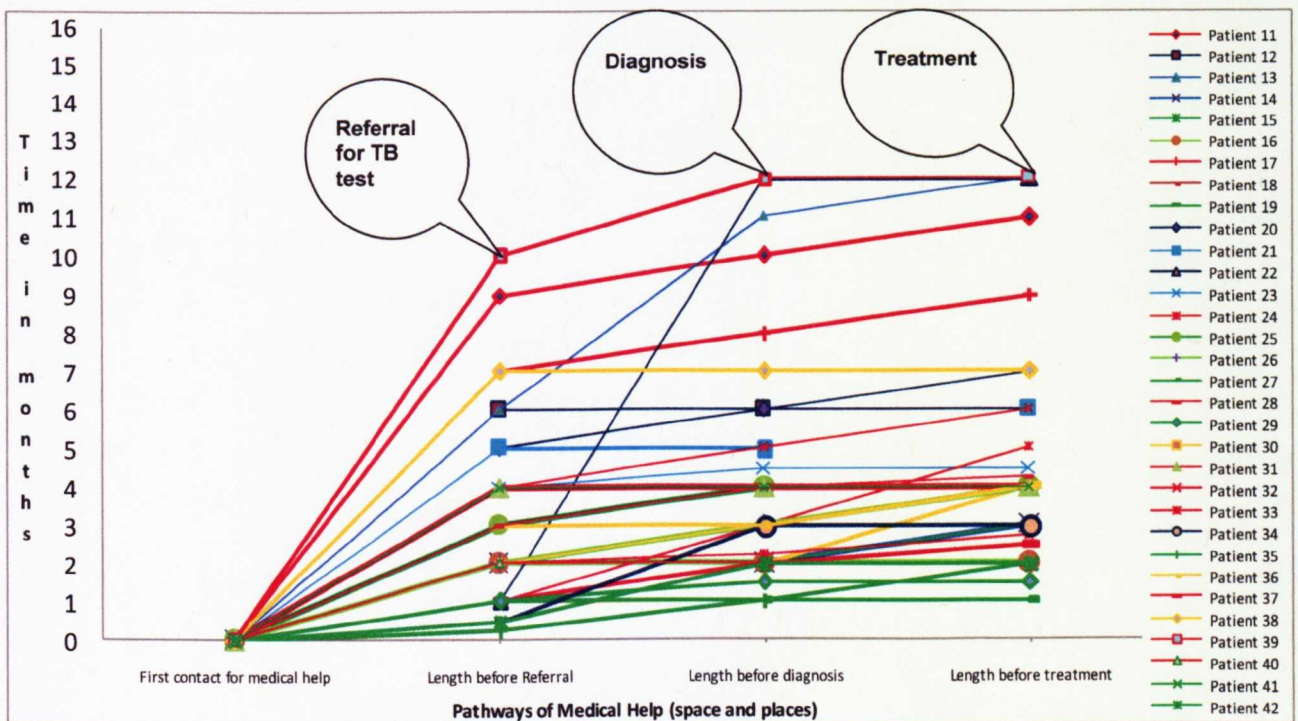
The overall experience of patients' journey resembles **r**-shaped (see Figure 10), climbing through barriers of communication towards a more straight line turn to rapid transition to TB treatment. Each graphic line contains one of the five colours chosen for groups of patients: green (*accepters*); dark blue (*doubters*); light blue (*coercers*); amber (*tolerant*) and red (*for the sufferers*) and that will be discussed in Chapter 5 of the analysis. Using colour coded graphic lines, the curve for some patients is much steeper in the red (**r**) rather than the curve for some patients as indicated in amber (*r*). The curve is much flatter towards diagnosis and treatment for some patients as indicated in green (*r*).

The above analysis in section 4.1 highlighted on time length taken by participants during their pathways to diagnosis and treatment and this has been useful for subsequent core story portrayal development. The research question this chapter sought to answer is related to the patients' experiential accounts of pathways to diagnosis and treatment. The section that follows presents the creation of core stories and the participants' experiences of medical help.

4.2   Analysis of core story plots and subplots

This section of analysis and results are specifically related to the first question posed through key stages in analysis. It will first look into the core story development process (section 4.2.1) from interviewees' verbatim transcripts and present five experience portrayals with key issue(s) contained in story 'plot(s)' covering each patient's journeys. In the second, the analysis of core story portrayals in this research (section 4.2.2), will identify plots and subplots from what each participant has told about his/her experiences. In the third, the results of narratives plots and subplots emplotment will identify key issues contained in story plots and subplots (in section 4.2.3).

4.2.1   Core story development

The development of experience portrayals (core story creation) was based on Emden's (1998) which coincide with keeping story intact for interpretive purposes as the basis of narrative analysis. In the process of core story creation, I found Gee's method of presenting narratives (cited in Riessman, 2008: p.35) useful which I applied in analysis of narratives during the pilot phase. (see Annex 2, p.236) The method involves deleting the interviewer (my) prompts and presenting narratives coherently as if the story arose full blown from each interviewee (Riessman 2008). My familiarity with Gee's method has been useful to follow Emden's method of core story creation which also involved going through similar steps to create coherent core stories. Key issues to this analysis were paying emphasis on time, context and content of each participant's experiences from his/her stories, (Emden 1998). As noted in Chapter 3, following feedback of core stories, comments from two narrators received were incorporated into the final experience portraits. I have included only five experience portrayals in this report to minimize the size of reading materials.

I will now ask the reader to turn to each narrator's core stories. I will first present the story of a non-English speaking narrator. Each experience portrayal also contains a short quotation and one of the five typologies: *accepter; doubter; coercer; tolerant and sufferer* and a text that underscores will be explained in more detail in Chapter 5 of the analysis.

Table 6:   Patient 19's   Experience Portrait

' ... I did not have bad experience they treat me well...', **(Accepter)**

Background (NES)
I come from Somalia in 2003 as an asylum seeker. I live with my husband and our seven children. I am registered with a GP. My doctor is very good she treats me well and I am happy with the health service. I used to live in Manchester and had a GP when I moved to London I registered with my GP three years ago

Triggers to seek medical help
In March last year, during the heavy snow fall I took my children out and when I came back home I felt cold and I started to cough. The next day early morning I went to my GP - and the GP she send me to this hospital When I went to see her (the GP) after feeling cough the night before the GP sent me to chest clinic for X-ray test that was some time in March last year the GP did not give me any medication. I was coughing nearly one week before she send me to this clinic.   **Plot 1**

Feelings and memories of first medical consultations
The GP said she did not know what it was and she wanted to investigate. It was an emergency appointment and my own GP was not in the surgery at the time and nobody knows about my case. That's why the GP did not give me medication. She just checked me over. She did not say much. I was coughing a lot and very ill. She just referred me straight away to the chest clinic. She refused to give me any medication so I was a little bit upset. When I went to see my GP the second time, she saw that I was referred for an X-ray. She prescribed some pain relief. I was so happy with that.   **Plot 2**

Referral pathways for further medical help and tests
After the GP referred me here (chest clinic) they took my chest X-ray. After that there was a little bit of delay for the X-ray report – I waited for nearly three weeks. It was in early April when this happened. The consultant said my X-ray report would be sent to my GP. When I went to see my GP, she said she could not see any problem from the chest X-ray and I was still coughing and feeling lots of pain. She then prescribed some antibiotic tablets. After that the hospital sent me another appointment for a chest X-ray that was done at the end of April. They said the X-ray result was showing TB and they confirmed this in a letter they sent me. They sent the same information to the GP. They then booked another appointment for me and they showed me my X-ray. There was some smoke on my lung and something not clear, a shadow on my chest. At the time I was taking the antibiotics and I was feeling a bit better.   **Plot 3**

Undergoing TB diagnosis and experiences of medical help
I told the doctor (chest physician) that I was feeling a little bit OK the doctor then did a little bit of examination on my chest and he listened to my chest and he asked me if I was still coughing? I said to the doctor, I was not coughing but feeling pain on my chest when I breath. The doctor then said 'he will need to check with camera (Fluorscope) test' by another chest clinic doctor at Set1h1 hospital. He (another chest physician) put the camera in my mouth. When I had the test, I was feeling a bit dizzy and a little bit blood coming out of my mouth. I received another appointment in May. I came here (chest clinic) and the appointment was so close from April to May after April they start me on TB medication. They asked me and I told them I do not know anyone with TB I visited relative in Netherland in 2005 one of my cousins who had something coming out of his back and had lump on his back he went to his GP and had chest X-ray and diagnosed with TB he was not coughing he was also treated in the hospital. I do not know how TB is transmitted and what form of TB is infectious.   **Plot 4**

Medical help experiences after TB diagnosis
The first day they took the chest X-ray and after that result they said I had TB. Some time at the end of April they started my medication.I was so scared that I had TB, because I was living in this country for nearly six years I don't know I was so scared about it. You know we had a problem about TB in my country when person had a TB that people think his life finished and if anyone find out they make discrimination and they do not like to contact or eat together or come closer and they do not like to speak to a person with TB. I was so scared of people rather than thinking about myself or my illness. When I had the camera test and they talk about TB I refused even when they check my skin when they put in my skin my skin goes green they put on my left arm. After 10 minutes my skin on my arm had changed to green and they said that I had TB the skin test confirmed I had TB. I did refuse the first time but they told me after the test. If they said when I first came to this country in 2003 I had TB its ok, but after six years I was so wondered how I could have TB in this country. I did not think TB is in this country. I only know about TB - people come from Africa or Asia. Even my family said where did I get the TB and they said that is not possible. They have no problem with it they were very very supportive of me.   **Plot 5**

Medical help and treatment care experience
When I was told I had TB then I thought and reason, it was too much for me to take really and by the time I started taking the medication the pain on my left side of chest started to go away a little bit by little bit, after the tests the doctor said he will give me eight weeks medication and when I finish to come back for another from April to June I continued with my medication and got another appointmnent and came back and they asked me if I finished my medication They asked me how I was feeling and at that time I had no pain at all only I had itching and allergy reaction all over the body. They are very good people and helpful people and I thank them for that. When I was experiencing reaction to the medication, I told her (the consultant) she changed the tablets to stop allergic reaction.   **Plot 6**

The ending of the story line: feeling and thinking
My knowledge is I did not see anything bad experience they treat me well they caring for me well and they speaking to me well and I do not have any complain about the NHS for my side of the story.   **Plot 7**

Closure – coda
I've been on treatment for six months and today my case was closed and I'm discharged. I am very happy I finished my medication now I feel very fit and OK today.

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Table 7   *Patient 21's   Experience Portrait*

Just at home sitting and suffering from pain for three months… (Sufferer)

Background
I come from India in October 2008, I'm a student in London and I live with friends. I'm registered with the GP in the first week of April this year

Triggers to seek medical help choices and decisions
Actually in April I was coughing for about a month. I thought it was a common cough, but it was increasing day by day from April to June.. The cough started a week before I started my exam in April 12. I was not able to concentrate on anything studying at work anything from April, May June I suffered so much. In April I went to Walk-in centre and they gave me free treatment. I did not go to the GP I just went urgently I don't know the reason.

Plot 1

Feelings and memories of first medical consultations
The doctor (WC -GP) said 'take this syrup and you can carry on for week' and he also gave me injection for the weakness. I had the second time they gave me an appointment I went to see a doctor and I said doctor 'I am feeling not well coughing too much I do not know what ever it is ..... he said you were coughing for two months and he gave me some I think ... syrup I think so for the cough told me to take three spoons and some tablets.' I also bought from the pharmacy, a cough mixture nothing happened. I went back (this was the third time). They said 'my blood pressure was low ...they cannot find anything and to take another blood test'. I came back for another blood test and I gave blood two to three times they said two weeks and three weeks for results. After three weeks, they phoned me and told me to collect a referral letter. My cough was increasing all this time.After that I try to make an appointment to see the doctor and I went back and they said they cannot give me an appointment bcause they have given me a referral letter and cannot treat me. I was feeling very angry then.

Plot 2

Referral pathways for further medical help and tests
The doctor who referred me to Set2h2 hospital gave me tests but , he did not say anything. They just said about my blood sugar they have not said anything about my chest problem. I went to the Set2h2 hospital .. they gave me another blood test, blood sugar and an X-ray as well. They said 'I have to come back to hospital without food I dont know why they said I have diabetic and they said 'they want to put tube in my stomach'. They gave me another appointment - I went on the 10th June they gave me appointment for the 8th July. After the Set2h2 hospital, I came back home. Just at home sitting and suffering from pain. The pain was increasing and I had no treatment it just kept on day after day. It took three months since April when my cough started as a common cough from May June and July. It took three months before sending me to Set2h2 hospital. I was very worried about the Set2h2 hospital, they have given me appointment for too long I spent more time there.

Plot 3

Undergoing TB diagnosis and experiences of medical help
The chest physician phoned me few days after and said 'I had to come to the chest clinic'. I have taken my documents and came to see the chest physician and I told him I have been referred to the Set2h2 hospital and the chest physician said 'why I went to the hospital I have chest problem'. I told him that I don't know different doctors sending me to different places I don't know. I told him all my story and the test they have given me three times. He phoned them and cancelled my appointment. He told them I should have not gone to the hospital. He told me not to take any of their treatment I am having a chest problem. The doctor (chest Physician) It was in the afternoon he put the X-ray and showed me my X-ray, I do not know I'm not a doctor, I told him how I was feeling losing weight and sweating is always there and I cannot concentrate anything the doctor told me not to worry about it he said it is common in London. He told me whenever I go out he told me not to stand in front of another person when you cough. He said the bacteria can go into the other person he gave me so much information and that day I started the medication.

Plot 4

Medical help experiences after TB diagnosis
The 2nd week in August (16th August) I came here (chest clinic). I have been on treatment for three months. The day I came to see the doctor I started my medication in that evening when I came back home then weekly they given me treatment and three months over. I am having the treatment and I found this is better and they are giving me encouragement as well.

Plot 5

Medical help and treatment care experience
For the last three months I was taking lots of tablets and now the tablets have been reduced. I used to take seven tablets and now only take two tablets. When they gave me the tablet they told me that I may have some problems with it. Since I started taking them, I did not have any problem and no reaction. I am seeing here my supervisor (nurse specialist) he is a good person I tell him all what I feel   I don't need to see the doctor anymore. Two days ago I had a chest X-ray and they checked my weight I have gained 2 KGs and then they have changed my tablets. I'm now taking two tablets for two months that's it, it is treally good. The treatment is very good, they (nurses) call me every Friday and remind me when to come.

Plot 6

The ending of the story line: feeling and thinking
I was really angry about myself, for two months I was coughing and in June the TB started spreading. They only did blood test in April. I was sweating and coughing a lot and had lots of pain. They did not give me anything. Here (at the chest clinic) they started my treatment properly. Before the illness I was very active and doing things a lot from April when I started feeling unwell, I could not do anything when I feel tired and go to sleep 7:00 o'clock at night so I was feeling the effect of illness increasing in me day by day.

Closure - coda
I am really happy, in two months time IlI finish my treatment. The chest clinic staff are good to me I don't know about hospital but this clinic is very good they have given me good treatment. In January I will finish my treatment completely and the doctor have told me that. So I'll go back to India in March.

Plot 7

Table 8   *Patient 12's Experience Portrait*

I was then thinking how can he give me the drug and it might make me ill…(Doubter)

Background
I come from Somalia. I have been in the UK for three years. I live with my husband and we are expecting a baby. I am registered with a GP.

Triggers to seek medical help choices and decisions
It was in December 2008, I started to feel unwell. I was coughing a lot. I lost weight and started sweating in the night. I could not walk even for two minutes. In February this year, I went to my GP I told my GP how I was feeling. He sent me to Dulwich hospital for an X-ray.

Plot 1

Feelings and memories of first medical consultations
He said the X-ray was negative. He said 'I do not have anything I may have asthma'. I then kept going to see the GP, I could not sleep at night. I remember once I had to go to GP everyday. They said 'I had asthma and they gave me inhaler'. When I took the inhaler, I could not get out of bed I had to sleep all the time. I told my GP this is not my medicine. At the end of March I started vomiting, I cannot speak loud, I start coughing when I speak, vomiting, cannot climb stairs, cannot sleep at night

Plot 2

Referral pathways for further medical help and tests
The GP then referred me to King's in March this year. They wanted me to do breathing test for asthma. I could not do the test, when I breathe out I start coughing. They said 'I cannot do the test, They told me to contact the GP to refer me to another specialist'. Then the GP referred me to asthma specialist. They took blood tests for thyroid and everything. I saw two different GPs. One sends me for chest X-ray to Set3h2 hospital and the other one referred me for Asthma specialist. The GP was thinking asthma, when I told him I cannot breathe. I had asthma even when he referred me for an X-ray that's what he was thinking. I'm asthmatic but I told him everything. The GPs sometimes they do not understand you. If you have got TB think you have asthma. Since March I did not go to my GP I stopped going there. They contacted me for the pregnancy so I told my doctor here (chest clinic) and he said 'I can take the medicine'. I told them I am taking TB medicine. I'm not happy with the GP because he did not referred me to the right hospital. There are lots of people like me with TB they go through the same type of problem. In this hospital I was under another doctor. He also told me to go home because I do not have TB. .

Plot 3

Undergoing TB diagnosis and experiences of medical help
Before the GP referred me to asthma specialist, I was staying at my friend's house. I was ill and I called the emergency ambulance, came to the Set3h1 A&E. I saw a male doctor. He told me to have an X-ray and he read the result and told me I have got something in my chest. He also said I may have TB, because he said 'I'm young, I come from Africa, I was coughing for three months and I also lost weight'. They kept me for three days in hospital they took sputum three times, all came negative and they took blood, it also came negative. They said anyone who come to visit me have to wear face masks. I said I don't want to stay here, and the specialist said 'they will have to send me home if I don't want to stay in hospital' and they also said 'I have to sign if I wanted to go home' . I did write the letter to Dr. I did not like to stay, because they said 'I did not have TB', everything was negative, blood, X-ray everything. I was seriously feeling sick and worried.. became ill again …sicker more when seeing other people wearing face masks, I felt sicker more. In my country if people got TB it is very serious. I was thinking and saying to myself. Nobody come near me, eat with me or nobody want to visit me.

Plot 4

Medical help experiences after TB diagnosis
The X-ray was showing something in my lung, because I was coughing. That's why it showed somthing in my chest. After two weeks, I received a letter from X hospital. I had blood test, CT scan and I waited for three weeks for the results. The CT scan showing something in the lungs and also in my stomach as well. The doctor said 'he could not find anything... I've got TB but everything came negative'. He said 'he cannot take risk' and he made a decision to start my TB treatment on the 6th of June. I was then thinking how can he give me the drug and it might make me ill. I told my mum, she said 'it may be TB' and my brother also said 'it might be TB' . I started treatment on the 6th of June. I waited from the end of March to June for two months. The Set3h2 hospital asthma clinic also sent me a letter to see asthma specialists. At the time I already knew then I had TB in this hospital. When I got the letter, I told them I do not have asthma I only go when I have asthma.

Plot 5

Medical help and treatment care experience
When I start taking TB medication, I felt dizzy, tired and vomiting after food. After two months I felt a lot better no cough, no tiredness, no fever, no skin reaction and a lot better afterwards.

Plot 6

The ending of the story line: feeling and thinking (Sharing the story told by a friend)
I got a story from my friend about an Australian man who lives here (London). He went to his GP so many times and his GP had tested him and all negative all the time. He then went back to Australia the doctors found his TB. He said, 'if he did not go back to Australia he could have died in the care of GP' in London. I also wanted to go to private hospital but I could not afford to go to private. I know some GPs are good but most are not good.

Feelings now and about future: Closure
I'm so happy about what the doctor did here (chest clinic). He decided to start my treatment. If he did decide based on the test results, I would have died really. All the test results were negative everything. I am happy very happy now. I am thankful for the NHS and to my doctor here (Set3h1 hospital). My friends keep asking me what has happened to me they said 'I have changed, I stopped coughing and put on weight and feel better after treatment'.

Plot 7

Table 9 Patient 23's Experience Portrait

' I said, I do not want no more antibiotic now… I want referral for chest X-ray', (Coercer)

Background
I come from Portugal. I have been in UK for two years. I work in a factory in London.

Triggers to seek medical help choices and decisions
It all started in May. I was coughing...coughing and coughing a lot. I couldnot sleep at night and the chest was hurting, and had problem with my breathing as well. I used to play football with my friends, I could not run I told my friends and then I went to my GP. I first went to the GP I do not know, it was the begining or end of May. I told my GP I started coughing a lot, cough with phlegm. He said 'I should take a cough syrup'. I also thought it may be due to weather changes. Whenever I had the syrup I used to feel normal for a week or two weeks then I used to cough a lot when the syrups finished the cough was still the same and I went to pharmacy and told them because the cough is keep coming up they give some more syrup. — **Plot 1**

Feelings and memories of first medical consultations
I took the syrup for about one month. I went back to the GP again, I did not feel well and it was getting worse and worse. The GP said, 'I can take antibiotic'. I went back to my GP and told him I was coughing and coughing. He just said that, 'have more antibiotics'. That's what happened for about three months. Every time I go there, he said, 'still have another course of antibiotic'. Then, I said, I do not want no more antibiotic now. .He was writing some more antibiotic. Then he said 'I should try this one'. Then I said I've been taking that for one and half months already, it is not improving. Then I took the antibiotic for one more time it is still not improving. — **Plot 2**

Referral pathways for further medical help and tests
I went back again and I said to him 'this is not helping I'm still coughing'. I said to him 'I want him to refer me for the chest X-ray, I wanted to do an X-ray nothing else. I said, I do not want any more antibiotics. I knew that there was a problem on my lungs. That's why I was coughing. Then he said, 'I should wait for two weeks then I will go'. I said no, I have been waiting for one and half months or two months, if I do not go now, it will go worse. Then he wrote me a referral letter, and I went for an X-ray. The GP is OK, but you need to talk otherwise no chance. If you need treatment you need to put pressure on them. If you do not put presure on them, they will not allow you to get through the system. If I did not put pressure on him I'd have been the one getting problem not him. I was referred by the GP in the middle of july or the end of July. I went to the Set1h1 hospital on the same day. Then as soon as the X-ray was done they told me to go home. After one or two hours they called me back. I went back they showed me on my X-ray I had a circle on my chest on the left side it was shadow circle. — **Plot 3**

Undergoing TB diagnosis and experiences of medical help
They admitted me for one day or two days. I had glucose injections while I was in the hospital and they took blood as well they took sputum test as well. I never had skin test. They found TB from the sputum and the doctor told me...he goes that he checked the sputum and X-ray and he said I had TB. In Set1h2 hospital the doctors told me that by the coughing you can find out.I asked them what was happening to me for two days. They said they do not know. I said they should know, they don't need to tell me they don't know. Then the chest physician came from chest clinic with other doctors. He told me 'I should come to chest clinic'. I asked him I wanted to know what it was the problem. He phoned me and told me that I had TB. — **Plot 4**

Remembering past experiences after TB diagnosis
I was confused, how I got the TB. I know people from Asia gets it. I have been to India on holidays two years ago for two months. I had all injections before I went so I would not get infected. When I came back I was OK. It was a kind of shock, I felt at the time. What was wrong? What was happening to me you know. Why it happened to me. All that you know, and then I got confused, but slowly, slowly, I got back to normal. When I came back from India I was working normal. In my work place, I heard people were saying that, some people had TB. If they have got it, they did not tell anyone they have TB. They hide it... I think, I got it from my work. I know it but I do not know where I got it from it is difficult to know. I told the nurse where I work in the factory and she said that she has got a couple of employees on treatment for TB. She said 'I may have got it from them'. In smoking area people always cough, so you cannot really say, everyone coughs in a normal way. As soon as I came here (chest clinic)I read about TB and I knew that, if I take the medicine I'll be cured. — **Plot 5**

Experience of medical help in chest clinic
The staff here (chest clinic) they are highly qualified you know. They treat me well and told me quickly what my problem was. They are helpful they write down everything for me in sentences. Even when I was in hospital as well, they did not give me medicine because they were thinking of a 50% chance they said they would not give me antibiotic until they were 100% sure of what it was. I told the hospital doctorsl my GP gave me antibiotics for long time. They said he should have found out before starting treatment. It was the GP who had done that to me I'd have been to hospital long time.

Medical help and treatment care experience
Then I came here and he gave me medicines. I had to take eight tablets. I did not take tablets all my life. I never had to take tablets, suddenly lots of tablets. The nurse has told me that, I'll need to take that for two months and after that the tablet will be reduced. I started feeling better after treatment. I was coughing a lot after coughing the phlegm comes out .It was hard chesty one, .no blood in it. I keep coughing coughing all night, I couldnot sleep my chest was hurting, my body was feeling hot as well. After I started the TB treatment for a month, it all started to slow down. After the second month may be one and half month, everything was Ok. I stopped coughing but was still taking the tablets. When I came to chest clinic I was 40KGs before I got ill my weight was 60 to 62 KG then I lost about 15 to 20 KGs. Now I've gained quite a lot, it is 68 to 69 KG. I gained more than before and I'm feeling better now. At the moment I'm taking only three tablets. I've no side effect. — **Plot 6**

Closure: *the ending of the story line, feeling and thinking*
The NHS staff are helpful and they support me all the time. As soon as they checked it here (chest clinic) they treated me well and helped me well. I'm alright now, I don't cough anymore, I have got another two months treatment left. In four months, I started to feel normal. If I had to do it again, I would do it again, and there is no problems. — **Plot 7**

Table 10   *Patient 38's Experience Portrait*

*'I am quite a tolerant patient…if you are polite to some one they polite back
, as a patient I did get along well with them.'* **(Tolerant)**

Background
I'm basically Bengali a house wife mother of three children. I was born in UK my parents both are British.

Triggers to seek medical help choices and decisions
It started like as a normal virus everyone gets a cough and cold and phlegm. I was not getting better for about a month I took paracetamol not working so I said I should go to the GP. I think it was it was in May 2008. I contacted my GP and I had my first chest X-ray.   Plot 1

Feelings and memories of first medical consultations
The doctor (GP) phoned me back. He realized on the X-ray it was not normal. He said 'I got infection he told me to come same day he got something to talk to me about. So I went, he said 'I have got pneumonia' so he said 'I have to take care and gave me advice and antibiotics. At the beginning, the GP thought it was pneumonia so the X-ray result suggests, I should start the pneumonia medication. I took that for three months. After I finished that, I went for another chest X-ray. They said it was more or less the same. So he (the GP) gave me another course of pneumonia medication, so one course is not enough so I should try another course. The GP then kept on asking me how I was feeling. I was going to see him monthly. I did tell him I did not feel better. Then suddenly, I started to feel worse and I thought to myself well I cannot be going on like this. I could not walk to the town centre and I cannot be going like that anymore.   Plot 2

Referral pathways for further medical hep and tests
He then referred me for chest x-ray and blood test to be done from there they found out one of my lung was severely damaged a lot of infection there. So they said it might be pneumonia TB did not come to their thoughts because pneumonia is more a less the same symptoms. The GP then said I may be having a bit of TB, he thought it might be TB even though he was treating me for pneumonia.   Plot 3

Undergoing TB diagnosis and experiences of medical help
He then sent me for emergency admission at the Set3h2 hospital. I was admitted for pneumonia they checked blood and asked me my history. I told them everything; they also suspected it might be TB. Out of nowhere you know, they all wearing masks and and I was admitted for two or three days. I started to bring sputum then they checked my sputum. A day after they said 'they could not confirm it from the sputum, but it might be non infectious, so they might need to do a long procedure'.The sputum itself confirmed so they started me on TB medication and discharged me the following day it was on the third day I think. The medication I was given was for a year but I did not complete it. I had about four or five months left before I was admitted at Set3h1 hospital in July. I think I did about six months worth of treatment six seven months worth out of the twelve months course   Plot 4

Medical help experiences after TB diagnosis
For about six months in the chest clinic, I was under different consultants at the chest clinic. There I was taking TB medication. I was on monthly or six weekly follow up. The consultant asked me if I am bringing up sputum still, I said yes and I was feeling chest pain you know because I was coughing a lot basically there was no changes. The first time I went to clinic, they tested all the medication and one of the first line medications did not work. They had to swap, so they gave me the different ones it was a long process. So all medication they tried did not work. In the X-ray they realized that my left lung was severely damaged, so they did not think it will repair itself. The shadowing of the lung all wiped out they hardly see the lung. In the right side there was a little bit of infection on the right lung.   Plot 5

Medical help and treatment care experience
So they referred me to the Set3h2 hospital consultant for operation. The wanted to get rid of the left lung, scarring and lots of infection, so that was the only way to get me better. At the end of June 2009 the operation is going to be done they planned it all out in the letter and everything was to be done at the Set3h2 hospital. So June came along and gone July is almost here. What was happening? They said 'I need the Isolation room so they cannot actually admit me until they get an isolation room'. I'm still TB positive so they cannot do the operation. The GP phoned me up, he said 'I had to go to hospital as an emergency they got an isolation room'. The day he phoned me, I was admitted not at hospital Set3h2, at the Set3h1 hospital, in July last year 2009. I thought I may only stay for two weeks. I ended up staying for three and half months. Well then again, the new treatment started in early July and they added extra multi-drug resistant TB medications. I had injections, in the drip which I forgot the name but stronger medications to get me better. The medications started working, seen signs of improvements from about a month afterwards. Since then I have not been going down slightest, only ups. It was obviously a slow process it's been a long time. So I'm not infectious, after three and a half months they were able to discharge me.   Plot 6

Eexperiences of medical help while in isolation in hospital
The nurses were happy with me. I am quite a tolerant patient, I was not being rude obviously if you are polite to some one they polite back, as a patient I did get along well with them. In isolation, at first I felt, I was covered in, I did not like it. Everyone had to wear aprons; it gives a different picture to someone. They just scared. My visitors had to find out I was infectious. They did not know the full history I could read from their faces a bit more cautious. The only thing I would have been happy they did not tell me I'm going to be in hospital for that long. My children cannot go even in the room the masks not fitting them properly they were not allowed. I could not see my children that were very depressing at first. They realize I am going to be here for a long time, it was in July, it was hot summer day. So I could go out and meet them outside in the open air, not too close only get to see them play.

Coping with TB treatment side-effects
To tell you the truth when I think about it still saddens me. I'm taking all my medication, I do not feel 100% I only feel better when I'm lying down. I'm not thinking about anything, that's how I could tolerate, even TB medication is hard to tolerate. When I started taking medication, one of the medications is called Pyrazinamide and that gave me lots of aches and pain. When I first took it, I could not walk, I was shuffling. I actually got disability living mobility allowance because of that. I've not been able to give my children more attention I was weak. They want me to help them with the homework which I cannot. Most of the time, I feel disappointed with myself for not been able to help my children and my family. My husband is doing all the cooking and the cleaning for the last two years. I feel depressed for letting my husband do that. He is not a well man. He has Insulin dependent diabetes; I was not offered support even when I was in hospital. The only thing even now every month I have to come for treatment here (Set3h1 hospital) from... it is quite difficult.

Feeling about being non infectious
Well I feel much better am not infectious one big thing I know now. I could mix with people without you know thinking about infection. I did not want to be close to people did not want to put anyone the way I've been through you know.

The ending of the story line: feeling and thinking
Basically I live on one lung now. By the time they found out my TB it was so badly damaged. It took six to seven months before I started TB medications. It took six months on pneumonia medication before the second X-ray. The X-ray took two weeks or a month later. I think that causes my lung to damage.

Plot 7

If we all suspected it was TB from the beginning, then I would have been able to start treatment earlier. I think it may even have not been multi-drug resistant TB. It was a minor TB; the normal medication would have worked. I think why it is becomes multi- drug resistant and infectious the normal TB medication did not work. I do not know. From my point of view, I took all my medication regularly because I want to get better. They usually say people who are missing their doses and do not take regularly it becomes multiple resistant. I took all the time and everything my stories are based 100% what I know then.

For my operation, they said that 'once my TB is all completely cured, after two years they will see how I'm tolerating and they might still consider that. My left lung is so badly damaged, and it has moved to one side not much difference they do not think it repairs itself unless a miracle happens.

4.2.2   Identification of narrative plots and subplots

This section discusses the identification of plots and subplots from core story experience portrayals. The plots and subplots are related to the first research question posed below. As noted in Chapter 3, the content of what the storyteller has said about her/his experiences are understood through 'plots' that characterize what the teller wants to convey and also understand.

Question: What did the patients say about their pathways to TB diagnosis and treatment?

The identification of plots and subplots was achieved through a process of core story experience portrayal development. I began looking into the core stories for temporality meaning 'a causal and connected sequence of events' (Riessman, 1993: p.41).

Identifying the location of each plot and subplot involved looking for this sequential ordering of events and the relationship between them (Good, 1994: p.144). Emden states that the process of a researcher developing a core story involves applying tacking and emplotment in putting together one coherent story that flows in a chronological sequence and discloses the meaning contained in the plot. I have applied the steps suggested by Emden for identifying the location of narrative plots and subplots within a story in order to make sense of the significance of the story as a whole is called 'emplotment' (Emden, 1998). The identification of subplots that together create one coherent story contained in the 'plot' (tacking). In Table 11, I have provided the constitutive definitions of the narrative concepts. I have highlighted in the five experience portraits included above the location of plots in the story for the purpose of transparency.

Tab 11 Narrative Concepts and Definitions

Narrative Concepts	Constitutive Definitions
Core- Story	Is a means of reducing full length of story to shorter stories to aid the narrative analysis (Emden 1998).
Plot	Is a linguistic expression that produces meaning through temporal sequence and progression as the heart of the story contain main point(s) (Emden, 1998).
Subplots	Subplots are part of a plot that articulate the complex threads of activities a plot weaves together to make a single story (Emden, 1998).
Tacking	Is a process of identification of subplots within the narratives by reading reduced text for sense, identifying fragments of complex threads of activities, 'moving back and forth' to identify specific issue(s) that articulate a single story (Emden, 1998).
Emplotment	Is a process of working with one or more plots of a story in such a way that the significance of the story is disclosed (Emden , 1998).
Plot Types	Archetypal forms (Typologies): are classifications of the teller's expressions and descriptions of his/her actions, behavioural patterns and complex activities in one of the many ways we attach meaning to others. (Riessman 1993, p17). Schutz describes this as a product of our shared meaning through which we use 'typifications' – the concepts attached to classes of things we experienced with others and even experiencing ourselves (Haralambos & Holborn 2000: p.1061).
Narrative Analysis	Operational Definitions
Stage 1. Core Story emplotment	In this research the 'core-story emplotment' is involved identifying plots from each experience portrayal of a person. Analysis involved, grouping plots by a generic plot label and then examining the structure of each plot for specific issue it articulates. Through the process of tacking analysis is further involved revealing specific issues and classifying them into sub-plots. In this, the data analysis approach is descriptive because of the emphasis is to reveal the teller's descriptions of events from what is told and happened (Emden 1998).

By working with one coherent story (plot) I intended to identify the significance of the story and key issue conveyed in order to disclose it. Going through each core story portrayal, I was able to reveal numerous issues from thirty two experience portrayals. I then grouped specific issues contained from narrators' experiences. In order to manage specific issues contained in the thirty-two narrators' stories, I needed to create a more generic name for

plots that refer to the same experiences. The specific issues I have identified then become the subplots of each plot I labelled in generic terms.

In summary, each plot is labelled in general terms in order to ease the management of plots generated from 32 core stories. In each plot, specific issues articulated in its 'subplots' were revealed and grouped in order to generate the results of the analysis. The analysis generated seven main plots containing thirty subplots, and each subplot encompassed one specific issue contained within the parent plot (see Table 12, p.109).

4.2.3 Results: narrative 'plots', 'subplots' and emplotment

In this section, I will present descriptive data containing quotes from participants' core stories, arranged in seven main story plots containing thirty subplots. The general approach I adopted was to induct themes from the data rather than focus on themes applied from theories and literature (Riessman, 2008).

In so doing, the data will speak for itself, as each subplot is carrying one specific issue about the plot. (see Table 12) In stage 3 of the analysis key 'subplots' identified from this section will be analysed thematically. I began the analysis by looking at the pathways to healthcare, the narratives suggested that differences did exist between the participants, in that some patients sought medical help from the hospital A&E and Walk-in Centres, while the majority of participants sought care from their GPs. Below is the first plot that contains a decision to first seek medical help from somewhere other than a GP. As noted earlier, each narrator's quotes are also labelled as one of five typologies: accepter, doubter, coercer, tolerant, and sufferer. These typologies will be explained in Chapter 5.

4.2.3.1 Plot one: First healthcare contact experiences and decisions

Narratives suggest patients' decision to seek first medical help from A&E and WC was based on many factors as described by the patients. Participants described the reasons for deciding to seek medical care from the hospital A&E or WCs contained in three subplots below.

Sub plot One: Difficulty in registering with a GP or obtaining appointment with a GP:
Patient 17, 18, 35 and 13 spoke about their difficulties.

> *"When I tried to register with them (GPs) ... they could not take anybody without an ID sort of thing." (pt.17 - Sufferer)*

> *"Registering with a GP...they are asking for the document I tried three times in Wembley... I could not get appointment properly," (pt.18 - Tolerant)*

"...I was ill, cannot breath. The GP gave me appointment for a week ...coming back I was sitting at the bus stop and I collapsed ... then taken to the hospital as emergency." (pt.35 - Sufferer)

"I had a swelling and pain in my elbow cannot do anything. I phoned my GP ... appointment ... was so difficult. ... So went to the A&E at the S11 Hospital." (pt.13 - Coercer)

Sub plot Two: Personal choice: preference and convenience

Narratives suggest that personal choices, convenience for urgency of care and free treatment were reasons to seek care elsewhere, as patient 20 and 33 explain:

"... personally I do not think there is a need for GP they do not know. They never ever diagnose the problem ...so I went to WC..." (pt.20 - Doubter)

"I feel very weak, feel feverish and I lost appetite completely then I went to a Walk-in center near my work...." (pt.33 - Sufferer)

Sub plot Three: Personal choice for urgency of consultation

Patient 21 spoke about his reason was due to urgency of care and free treatment

"...I went only to S2 NHS WC ...I just went urgently I don't know the reason ...they gave me free treatment." (pt.21 - Sufferer)

Patient 25 the decision was made by her husband related to urgency of care need:

"In February ...I fell down and hurt my head ...and suffering from severe headache. my husband brought me into the S11 hospital A&E ... "(pt.25 - Accepter)

4.2.3.2   Plot Two: First contact: memories of medical consultations

Narratives contain the patients' experiences of communication with their doctors and feelings and memories of their medical consultations in the extracts grouped into four 'subplots'; each one illustrating an issue about the plot.

Subplot One: Telling them everything but was not understood

Some patients also described their contact for medical help involved a considerable time period and being misunderstood as the quotes explain:

"In May 2008 I noticed a small soft bump... It felt like needling pain ...unbearable and restricts...my movement. I went to my GP for long time between May to October. ...what he thought was happening and what I was complaining about was wrong in the end ... misdiagnosed me...." (pt.11 - Sufferer)

"I started to cough in November 2008 coughing and vomiting...I never ever stopped. I cannot sleep, I lost about twenty KGs. I told him in my simple knowledge, 'The cough is different from ordinary coughs,...I told him (the GP) 'I am hot, I am very hot please do something, please do something'. I cried all the time...for many months," (pt.39 – Sufferer)

"I lost nearly a couple of months going back and forth to the GP. The GP was thinking something else she told me it might be cancer. The blood test shows nothing ..."(pt.32 - Sufferer)

"I was coughing a lot and had a temperature. I told him everything. He (GP) checked my temperature, he listened to my chest. He said 'my chest was clear' and for the cough he gave me Amoxacilin. I took the antibiotic ...feeling very very ill. When I coughed, I started to vomit, that make me rush to the S22 hospital A&E". (pt.33 – Sufferer)

"From October to January the GP did not refer me to hospital. I explain to the GP the pain killer only stops it may be for couple of hours ...I used to go to the GP every week..."(pt. 37 – Sufferer)

"I was coughing and my throat was hurting and all that. ...my GP checked me and he said 'I've got a chest infection so he gave me antibiotics", (pt.31 – Sufferer)

"I felt pain in my fingers that was unbearable and restricting from me doing anything. My GP only gave me pain killers. Then I had swelling in my arm got bigger and bigger...change its colour... became pink and started to go green", (pt.24 – Sufferer).

Patient 27 spoke about how her concern about TB risk and her GP had not taken it seriously.

"My sister's husband had TB he told me I should go and have TB test because ...I had the same condition. ... "I told my GP I cough a lot, had a fever, felt cold and cannot eat well. He told me 'it could be a problem with the weather, it was nothing....'" (pt.27 – Coercer).

For two patients their illness symptoms were not adequately understood by their GPs.

"I started to cough ...sweating at night, I lost weight. I told my GP that I may have TB. He said 'It doesn't look like I had TB, but if I was worried about it he will send me for a chest X-ray", (pt.26 – Coercer).

"My experience with my GP was that I was asking him about the pain in my stomach and the GP was not listening to me properly, he thought it was a gastric problem". (pt.40 – Coercer).

For patient 36 her symptoms were linked to a seasonal Flu illness by her GP.

"When I entered the room, the moment she (GP) saw me she asked for the mask. She actually said to me it has to be Swine flu'. I just said oh god! I had to collect the prescription for Tamiflu...."(pt.36 – Tolerant).

Three patients spoke about their experiences of not being taken seriously by professionals.

"I told my GP, 'I was having temperatures'. He said, I should have ...rest and take some paracetamol'. I then started to vomit fresh blood. I...told him, that. He said 'no because I'm trying to vomit'. I said, 'I did not vomit with my pregnancies'. That was completely ignorded by him...." (pt.30 – Tolerant).

"I felt numbness on my left side of my arm ... my friend took me to the A&E. I was a bit upset you know there was a bit of delay at the beginning...they would have seen me quickly and would have done something..... " (pt.18 – Tolerant).

"About twelve weeks ago I...complained about pain in my knee and I kept on going and going and going and the GP said nothing he can do about thirteen weeks ago." (pt.42 – Accepter).

Patient 28 spoke about what his GP thought was just an infection:

"The GP thought it was just an infection. He gave me antibiotics......appointment for blood sample ...four weeks went...The tumour in my neck was growing ...I started to get fever at night...he then referred me to ENT ..." (pt.28 - Sufferer).

Patient 16's GP thought it was a dust allergy:

"I started to cough a lot, my GP said, 'it could be a dust allergy'. ....So he said, 'I should take antibiotic for a week I will probably be fine'. ...then I started to have fever and coughing a lot" (pt.16 – Accepter).

Patient 17 was sought care from an A&E doctor.

"I started to have a severe cold, cough with phlegm and it started to get worse. I went to see my GP in Hackney ....they won't put me back on their list. I then went to Homerton hospital A&E...."' (pt.17 – Sufferer).

Subplot Two: Being told to keep taking antibiotic that did not help

Patient 14; 26; and 31 described that their GPs' treatment for their coughs was only antibiotics that was unhelpful.

> "I started with lots of cough fever and weakness ...I took herbal treatment for about one month ...I went to GP two to three times they GP gave me antibiotics but it did not help. (pt.14 – Coercer).

> "It was in August at the begining of August I saw the GP he gave me antibiotics for two weeks I think I took it for one week but it did not help," (pt.26 – Coercer).

Patient 31 coughed with blood and given antibiotics for chest infection:

> "I was coughing ...and coughing and I went to see my GP again and I said my chest is hurting and when I cough, blood comes out...'. He then checked me and said, 'I've got a chest infection ... So he still gave me antibiotics and I took that medication and I went to Africa." (pt.31 – Sufferer).

Patient 33 and 17 sought help from a Walk-in Centre and an A&E were only given antibiotics.

> "I feel very weak, feverish ...I went to a Walk-in Center ...I was coughing a lot and had temperature I told him everything ... he said my chest is clear, for the cough he gave me Amoxycillin...," (pt.33 - Sufferer).

> "I went to the Homerton ...they said that 'I had a chest infection' ...so I took the antibiotics for ten days it did not help. I also went to St Mary's A&E they also gave me antibiotic that did not help either." (pt.17 – Sufferer).

Patient 30 spoke about her experience of medications for Swine flu and her GP was not taking her concern seriously:

> "My temperature was high ...I was told I had Swine Flu, I had Relenza for three days... after a week they gave me Tamiflu. I keep phoning them every morning, vomiting fresh blood. One of the GPs said it's infection gave me antibiotics. ...I was vomiting all the time..." (pt.30 - Tolerant).

Subplot Three: Complaining same problems and lost time on unhelpful treatment

Many other patients also describe that, despite complaining about the same problems in several contacts, they were only offered either symptom reliefs or painkillers.

Patient 20:
> "I almost ...died ...I could not breathe ...I went to the Walk-in Clinic told the nurse ... "whenever I breathe, I had difficulties on this side (left side of body)" ...she said I should not worry it is a muscular pain ...'thoracic muscle spasm', told me to take nurofen...I took that for long time," (pt.20 - Doubter).

Patient 39:
> "...I told him (GP)..."I feel very hot please do something, please do something. 'I cry all the time. He only gave me cortisone antibiotic syrup for many months," (pt.39 - Coercer).

Patient 11:
> "From May to December, I went to GP for long time...In December, the pain is getting worse. The GPs said they could not do anything, only give pain killers. ..." (pt.11 - Sufferer).

Patient 32:

> *"Upto three times a week complaining about the same symptoms....but they (GPs) give me painkillers another pain killers ...I lost nearly a couple of months going back and forth to the GP. The GP was thinking something else. ....". (pt.32 - Sufferer).*

For others, their GPs told them that their illness are not serious only requires them to take painkillers.

> *"When I rang them (GPs), they always say to me I don't have anything... just take paracetamol bla...bla...bla. I was so serious" (pt.13 - Coercer).*

> *"... I took herbal treatment for about one month ...before I went to GP. Then I went to my GP two or three times. The GP gave me antibiotic medicines but it was not helping..." (pt.14 – Coercer).*

> *"After I had the X-ray....I went to the GP several times. The GP gave me medicine for gastric. He thought it was a gastric problem but it did not help,' (pt.40 – Coercer).*

Patient 37 and 42 spoke about how their GPs did not refer only offered painkillers:

> *"From that October to end of January the GP did not refer me straightaway. ... I said to the GP this thing is not normal...I kept telling them that this pain is getting worse," (pt.37 - Sufferer).*

> *"I was having pain in my knee and I used to go to GP for the pain and the GP used to give me medication every week" (pt.42 – Accepter).*

Subplot Four: Telling illness symptoms, not being given right medical help

Narratives suggest the nature of medical help experiences by some patients involved undergoing routine tests by the doctors (GP/WC and A&E) that were unrelated to patients' real concerns.

Patient 27:

> *"He told me it is just a weather problem I told him that I had to travel to work too far and I was tired and all that he just told me it was just a weather problem it was nothing. He told me I had an X-ray once before, (pt.27 – Coercer).*

Patient 30:

> *"I went to my GP and I was having temperatures...I had all this flu like symptoms, aching body and temperature. They (GPs) thought it was swine flu; they just gave me Relenza and not Tamiflu because I was exepecting. I was given Relenza at home I had it for three days.." (pt.30 – Tolerant).*

Patient 22 and 13 spoke about their experience of long period of testing:

> *"I don't know... it's my back, 14 to 15 months ago my back pain started. The GP sent me to the hospiital to orthopaedic department at S32 hospital. The hospital they scan me and they said nothing and went back to the hospital nothing nothing nothing" (pt.22 - Doubter).*

> *"...In the A&E they could not find anything. The day after, I went there again and on third day I went again. The bone specialist admitted me and I stayed there for four days they gave me antibiotics and everything. They did the X-ray but nothing found they said nothing ..." (pt.13 – Coercer).*

Five patients spoke about their experiences of several contacts before referred by their GPs.

> *"The GP thought it was just an infection that was very very bad from my part. Then after I had taken the medicine it did not reduce swelling and the tumour in my neck was growing ...growing too much. I started to get a fever at night and when I went back again to the GP he referred me to ENT in S21 hospital." (pt.28 – Sufferer).*

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".I used to go to GP everyday as an emergency you know I was quiet ill I was suffering a lot and what the GP is used to say I need to go for ultrasound first he cannot say anything you know before they do ultrasound, (pt.24 – Coercer).

"I lost nearly a couple of months going back and forth to my GP. ....Then in January, I had a couple of blood tests at the GP. The GP said that, 'There was an inflammation in my blood and she did not know what it was." (pt.32 – Sufferer).

"I was coughing ...coughing and coughing and I went to see my GP again and I said my chest is hurting when I cough blood comes out ... He then gave me antibiotics and I took that medication and I went to Africa." (pt.31 – Sufferer).

"When I went to the WC first time I was coughing a lot and had a temperature I told him (GP) everything. He said 'my chest is clear'. So for the cough he gave me Amoxacilin antibiotics. I was feelinig very very ill. When I coughed I started to vomit and that make me rush to the emergency service." (pt.33 – Sufferer).

4.2.3.3 Plot Three. Referral pathways for medical help and diagnosis

The narratives suggest that the referral to diagnostic facilities is achieved in many ways, as the 'subplots' from the extracts below indicate. In these extracts each subplot contains one specific issue and grouped together as highlighted by subplot headings:

Subplot One: Quick (Immediate) referral to specialist by GP

Seven patients spoke about how quick referrals were achieved:
"I was coughing, sweating at night and losing weight and I had nose bleed ...I had swelling on my neck as well. When I told my GP that he said 'the symptoms is like TB so he referred me to the chest clinic starightaway'." (pt.41 - Accepter).

"I went to the GP and the GP said no problem ...and she sent me to the hospiital to orthopaedic department at Guy's hospital". (pt.22 - Doubter).

"Only contacted my GP once...He said, 'it might be TB he was not sure'. He then referred me to ENT. I said I cannot accept it, there was nothing wrong with me. I don't drink, I do not smoke and I do not have itching or anything and as a result my background is always so strong and clear. They said, 'It might be happening to anyone'..." (pt.34 - Doubter).

"....I went to the GP and I gave my urine and he checked and he told me 'my sugar was too high so he referred me toS11 Hospital'. I had the blood done and also had an X-ray test". (pt.29 - Accepter).

"In May I was so ill and had lots of pain. When I asked for an appointment with my GP, they said. 'They can only give me an appointment for next week'. I told them, 'when I breath, I hear the bubble in my chest I was in severe pain on right side of my chest'. They said I should go to the A&E. Coming back, I was sitting in the bus stop and collapsed ...I was taken to the A&E," (pt.35 – Accepter).

"I went to my GP for the swelling on my neck. My GP then asked if I had any other symptoms. I had no other symptom, only uncomfortablness on my neck. The GP said, 'it could be lymphoma'. He suggested that I should see a specialist. I did not know what lymphoma was I went on Internet and I found out it was a type of cancer. That really made me worried. After I saw my GP I got a call from the specialist within 10 days to have an ultrasound," (pt.15 – Accepter).

"My GP said, 'I'll be alright for awhile if I take the antibiotic'. It did not help me. He then called me and he referred me for a blood test and X-ray in the S11 hospital. The X-ray technician was very good. She found that there were some problems on the X-ray and she got the doctor to see me." (pt.16 – Accepter).

Subplot Two: Referral to specialist after unhelpful treatment

Patient 31, 33 and 37 spoke about their experiences of several contacts with their GPs and were given antibiotic for chest infection that was ineffective before their GPs decided to refer them:

"The GP said that, 'I have been coughing for almost eight weeeks. He said that 'he gave me antibiotics before' and I said 'yes'. He said 'he has got no choice but for me to have a test it is probably TB' He just mentioned it. I said OK and he gave me a letter and told me to come here (Shrewsbury raod clinic) for a test." (pt.31 –Sufferer).

"... I was ill I went to A&E as an emergency. The emergency doctor told me, 'I should go and see my GP the best thing my GP can do is refer me to the chest clinic so I went to my GP. He (the GP) then he referred me to S2 chest clinic". (pt.33 – Sufferer).

"Then I saw another GP, I said to the GP 'it is not normal my pain is getting worse'. He checked my body and said, 'he thinks something is wrong'. He said, 'I need to have an X-ray and told me to go straight to the hospital'." (pt.37 – Sufferer).

Subplot Three: Referred to specialist when critically ill

Some patients also spoke about their experiences of being on painkillers and antibiotics and how their illness continued to increase and finally reached a critical stage which necessitated a referral by their GPs. However, for some patients referral was made using wrong diagnosis classification due to wrong interpretations of the patients' illness history:

Patient 11 and patient 24 spoke about their experiences of painkillers:
"I went to S33 hospital twice... I went back to GP again I was in agony, could not walk, running hot and cold. The lump was growing the size of tennis ball, then they referred me to St Thomas's.," (pt.11 -Sufferer).

"It took to long to get the appointment....I used to go to GP everyday as an emergency you know I was quiet ill I was suffering a lot. The GP said... he cannot do anything before they do an ultrasound in February," (pt.24 – Sufferer).

Patient 28; 32; and 30 spoke about how their GPs misunderstood their illness:

"I was so sick during this time so ill, and weak I lost about 10 Kgs... the tumour in my neck was growing ...growing too much. I started to get fever at night and when I went back again to the GP. He then referred me to ENT S21 hospital," (pt.28 - Sufferer).

"It was in January. I had a couple of blood tests at the GP. It showed that it was negative .... For a couple of months after that, I started losing weight and losing my appetite. The GP then referred me to the orthopaedist doctor in S11 hospital....," (pt.32 - Sufferer).

"After that I got very ill, I could not go to surgery. The GP came home and then he referred me to the A&E.....I had some blood test and swab for Swine flu. There was nothing back from that. I assumed there was nothing found from it..." (pt.30 – Tolerant).

Subplot Four: Applying (putting) pressure on GPs to refer to specialist

Narratives from a number of patients highlight how they had to put pressure on their GPs in order to be referred for further tests. Patient 39 and 40 describe how they needed to put pressure on their GPs to refer:

> "I put pressure on my GP do something. I know when GPs sent a patient to the hospital they lose money. That's the main important things for them. It is not my health - it's his money that is important for him. So I told him I do not leave the surgery .... So he sent me to the S11 Hospital." (pt.39 - Coercer).

> "...I was feeling very sick could not sleep, my stomach was very painful. I went back to the GP and said if he did not refer me, I'll go as an emergency. He saw me, I was very ill referred me to the S21 hospital and that was the fourth time", (pt.40 - Coercer).

Patient 26, patient 27 and patient 14 spoke about how they were worried and demanded for referral:

> "I coughed a lot and had fever, and weakness. ... When I saw this other GP, I told her I want to go for a chest X-ray so she said she wanted to check first. She checked my breathing and my back and she said yes she will send me to the hospital for an X-ray to S11 hospital" (pt.14 – Coercer).

> "... I took antibiotics for one week it did not help. I went back, I did tell my GP that 'I may have TB', and he said, 'I don't look like I haveTB but if I am worried about it he will send me for chest X-ray' " (pt.26 – Coercer).

> "I went to my GP .... He said, 'it is a problem with the weather'. I told him I need an X-ray he said, 'I only go when its a problem'. He told me, 'I can go to any hospital if I need an X-ray'. He told me to make an appointment at the S11 hospital and gave me the number", (pt.27 – Coercer).

Subplot Five: Collapsed and taken to the A&E

The narratives suggest that after referral by GPs' some patients had to wait too long for a hospital appointment. While waiting for an appointment, some of these patients were critically ill and needed to seek urgent care from the A&E including travelling abroad:

> "So unless you collapse in the hospital or join the emergency, there is no good service available. That was my very very bad experience. ...in the NHS my experience is very...very...very bad." (pt.28 - Sufferer).

> ".... I started losing weight and losing appetite. I was waiting for referral to see the orthopaedist doctor in S11 hospital then too much after, they did not give me any treatment and they did not say exactly what, then I went home (Tanzania)," (pt.32 - Sufferer).

Patient 13 and 17 experiences of getting referral from GPs

> "When I rang them they always told me 'I don't have anything I should just take paracetamol... bla...bla...bla. I was so angry I had to fight with them. So, I had to do something, I had to go to other doctors I did not want to let my pain increase nor the swelling on my arm. That's why I went to the S11 hospital." (pt.13 – Coercer).

> "I went to the S33 hospital A&E. ... they said, 'I should go to my doctor and get a referral for an X-ray' I told them I do not have a doctor", (pt.17 – Sufferer).

Patient 20 and 25 chose to seek care from the A&E rather than from their GPs

> "I was told by paramedics to stay at home they said 'I had Swine flu'. ...One night my temprature went through the roof. I just kept coughing and coughing and it was just too much.

My brother called an ambulance. They did blood sugar test blood pressure and everything was low, they then rushed me into hospital to the S11 hospital," (pt.20 – Doubter).

"In February....I was suffering from a headache for about a week. My husband had to bring me to the S11 hospital a couple of times. First they sent me home with tablets, second time they admitted me", (pt.25 – Accepter).

Subplot Six: Waiting long after referral never received a letter

Some patients also spoke about their experiences of waiting too long after a referral and never receiving an appointment letter:

Patient 24:
> *"It took too long to get the appointment I was just waiting on pain killer for about two months. Finally, after two months, I went to hospital. They told me the appointment was next day. I never receive a letter, nothing. .I used to go to GP every day as an emergency I was quite ill ...suffering a lot ." (pt.24 -Sufferer).*

Patient 15:
> *"After referral I never received a letter from the S11 hospital. I called them up and they were able to trace back my details and they said ... appointment is definitely sent. I never received a letter. I think it might be due to postal strike." (pt.15 - Accepter).*

Patient 39:
> *"The GP said he referred me ... I did not receive anything. So, I went to the S11 hospital A&E. The doctor said, 'There is nothing in the X-ray and you are wasting my time'. I told him ...I coughed for six months and ...and am old woman severe asthmatic It is not wrong ...to come to see the doctor. He was speaking to me in front of the other patients...so I cried but he treated me very badly." (pt.39 - Sufferer).*

4.2.3.4 Plot Four: Undergoing TB diagnosis and experiences of medical help

The narratives suggest that issues about patients' journey to diagnostic facilities and their experiences of medical help from professionals: seven specific issues featured within seven 'subplots' as each subplot indicate.

Subplot One: Complicated pathways of referral: long waiting before diagnosis

Patient 22 and 34 spoke about their experiences of long periods of testing and waiting.

> *"I don't know the GP ... referred me to the S32 Orthopaedic hospiital'. In the hospital they scanned me and said nothing and I went back to the hospital nothing nothing nothing." (pt.22 – Doubter).*

> *"...the GP referred me to ENT at S32 and ...and the doctor in neck and throat clinic said it take three months or more. They took blood and drained out some pus for the test ... first and the second test, there was nothing ..." (pt.34 – Doubter).*

Patient 28 spoke about his experiences of delay after his GP referral

> *"after GP referred me to ENT in S21 hospital, I got seriously ill and collapsed in A&E at S21 hospital ...I was then admitted in S22 hospital ENT ...on day four, they sent me for skin test, that was after eight week long you know...the result was positive. Then they referred me back to theS21hospital ENT so again another appointment ...Then I came back to Newham hospital ...the doctor was not available. They referred me to S2 chest clinic. (pt.28 - sufferer).*

Patient 32 spoke about her experiences of months waiting and travelling home country:

"After the GP referred me to Orthopaedic specialist... I could not wait any longer so I went back home to Africa... I went back home (Tanzania). As soon as I got there, I just collapsed ...taken to emergency private hospital..." (pt.32 - Sufferer).

Patient 39 spoke about how her experiences after her GP referred her for illness associated with vomiting:

"...I saw the doctor. I explained to him my situation. He never ever listened to me and he said, 'the vomiting may be a problem in my stomach. He gave me some capsule that is the treatment. He never listened to what I said, (pt.39 - Sufferer).

Subplot Two: Undergoing long period of tests

The story about undergoing a long period of tests emerges in several accounts of the patients. For two patients, referral to hospital departments involved tests for several months.

"...from January up to May the swelling growing in me. ...I came three times as an emergency; they said I had to contact my ENT department. I said there is no treatment, it is only testing and testing for more than three months ...." (pt.34 - Doubter).

"...the GP referred me to Orthopaedic at S211 hospiital... they scan me and they said nothing and went back to the hospital nothing, nothing and nothing for one year. At last, I could not walk with my back pain very difficult to walk ...The doctor said I should have an MRI scan ..." (pt.22 - Doubter).

Patient 13 and 24 experience of long periods of testing:

"In July 2008 I went to theS11 hospital then continued going there for a long time one month here and 1 month there for long time. I don't remember ..I saw different doctors, swelling was on my elbow they thought I may have ortopaedic problem so they kept me with him for long time." (pt.13 – Coercer).

"It was on Friday when they checked me and admitted me here (S11 hospital). They took blood tests and then ...they were not sure of what it was. ...They did blood test and none of the tests found TB bacteria..." (pt.24 – Sufferer).

Subplot Three: Experiences of TB diagnosis

The narratives suggest that a long period of testing and the patients being told that their test results were clear appeared to have reinforced their doubts about their TB diagnosis.
Patient 22:

"...After one year, they told me I had TB Why? I think I cannot believe it ...the doctor said I had TB and the letter said I might. I had too many tests...CT scan and three to four times X-rays, blood tests, I don't know hundred hundred times blood tests" (pt.22 - Doubter).

Patient 34 described his reasons for not doubting his TB diagnosis:

"...when I saw the doctor in chest clinic he said it was TB. I know medical science has proved this and that. I have to accept what ever the medicine I was given. My mind has accepted it, but my heart has not accepted it. ... I had taken all my injections (vaccinations) as a child ... I do not have wrong habits, physically fit,...only lost a little bit of weight and my appetitie is OK.That's why I feel it is not TB." (pt.34 - Doubter).

Patient 20 her story seemed to be related to the test failure and doubting her skin test:

"I do not think I have TB ...because the only reason they give me this treatment because they did the skin test while I was in hospital...twice you know. What about if you put the needle in wrong way? It is going to increase the measurement'....that's why the swelling in my arm got bigger... I do not think they can use mantoux test to say I had TB..." (pt.20 - Doubter).

Narratives suggest that access to diagnostic tests for some patients was difficult and patients described their experiences of how they were able to achieve diagnosis.
Patient 17:

> *"I went ...St Mary's hospital. ...they said I should go to my GP and get referral for an X-ray I told them I do not have a doctor... then I went to the Citizen Advice Bureau ... and they sent me to the S31 hospital A&E department.They gave me an X-ray and ...they said straightaway I got TB. They sent me to the chest clinic", (pt.17 - sufferer).*

Patient 39:

> *"I'm grateful for a consultant...I begged him ...I cried 'Please doctor, I feel there is something ... I'm changed. I'm not the person like before' ... He did the scan, the sputum test, ... He saw me sweating so hot, so I told him I cried from my GP to the hospital ...I cannot say anything. I'm a muslim woman. I respect my God and respect people and let my God punish them." (pt.39 - Sufferer).*

Patient 13 described how her husband needed to fight for more test for her illness

> *"They did the X-ray.... They still say nothing there...my husband was fighting with them. He was telling them there is something there. That's why she had a problem she is dizzy and tired and they should check again. I had the CT scan and they found I had black spot on my elbow then referred me toS1 chest clinic." (pt.13 - coercer).*

Subplot Five: Experience of confusion between doctors' opinion and test results

Narratives suggest that the process leading to diagnosis for some patients also involved confusion; different medical opinions and uncertainty surrounding the diagnosis and the tests given by their doctors.

Patient 24:

> *"I was admitted in isolation room and they took blood test. ...then all the test, did not find TB bacteria. ... The doctor came. He asked me to do a skin test... did not find anything but, after they seen all my condition and symptom, the doctor said I have got TB and they started my treatment". (pt.24 - sufferer).*

Patient 20:

> *"I was discharged from S11 hospital in October .... After one week I became worse I was having fever at night ...shaking, could not breath...My lungs going to explode I just came back and kept asking the doctor am I'm dying...that was the first time I was seriouslly ill like that. They told me my culture will take about six weeks.I got a bit impatient, I am still taking my medication the pain is still there but I cannot feel it that much so that's why I donot mind taking the drug as long as it does what is supposed to. I hope I donot have to come to hopistal for any because it is a terrible experience you know" (pt.20 - Doubter).*

Patient 26:

> *"They took my X-ray and said I have to see the doctor .....The doctor told me he thinks I had TB. He told me that someone come from Africa eight out of ten chance I have got TB...in this country ..they look for safety, so that's why.- if he was in Africa, he will give me TB treatment".(pt.26 - Coercer).*

Patient 30 spoke about her experiences of not being given TB test:

> *"The first time I was admitted ...after three days, I was sent home without diagnosing it. I had all similar symptoms ....for another month. ... I came back ... then they kept me in for three weeks. ...I had blood test, chest X-ray and CT scan they ...do not always come back*

assuming it is negative... I told the doctors I lost weight, getting temperature, headaches and vomiting blood. They said my chest X-rays...was not brilliant so they referred me to chest physician...." (pt.30 - Tolerant).

4.2.3.5 *Plot Five: Medical help experiences after diagnosis and treatment*

The narratives suggest various experiences of help after diagnosis either during the hospital stay or after being discharged from hospital. The subplots below highlight either good or bad experiences told by patients grouped together under each sub plot heading:

Subplot One: Not taken seriously for information and care needs

Patient 22 and patient 34 spoke about their diagnostic process.
"They try to explain, but the main thing is I do not understand it ...they might say blue, red, yellow, but they don't say black and white." (pt.22 - Doubter).

"....it is taking long time and the ENT experience is very bad delay and ...the nature of doctors ...they did not have sympathy and friendly nature. They are just straight forward this and that then you go and not having the time to listen to my concerns." (Doubter – pt.34).

Patient 30:
"When I was in hospital I was very angry that I was not treated fairly by the nurses, I had to ask for my medications and I was not taken seriously...I also had no explanation about TB meningitis ...the leaflet does not explain about TB meningitis. The information is not great...." (pt.30 - Tolerant).

Patient 35:
"I was for one week on my own in a separate room ...I used to ask nurses to give me water for my tablets but they used to forget...I was not allowed to go outside. I used to wake up and pressed the buzzer ..." (pt.35 - Sufferer).
Patient 11:
"When I was discharged, I was really out of it. They did not keep in touch with me. ...I was trying to phone but I was not getting the right department. I ran out of medication. I had to go to the GP.I did not know I had to come here (chest clinic) to get medication... they did not tell me. I do not remember them telling me...." (pt.11 - Sufferer).

Patient 15:
"I think it has been great ...The only thing is, is TB a communicable disease? I do not know and no-one explained to me.. A bit of hiccup once in awhile." (pt.15 - Accepter).

Patient 36:
"When I was in isolation room, I could walk but they (staff) did not want me to walk outside my room.... So, I asked the carer, to collect the bin from my room. The carer told me that, 'I've got legs I should get up and throw them'. I just kept quiet and I did not do or say anything.".(p36 - Tolerant).

Subplot Two: Need for information adequately met

The narratives also suggest that the need for support and information was adequately met for some patients particularly during their tests and treatment follow up in chest clinics:
"They have given me very good information ...like the changes when I take the medication what changes I will see in my hearing (side effects)....very good instructions that were helpful." (pt.28 - Sufferer).

"They are very good people and helpful people and I thank them for that. When I was experiencing a reaction to the medication I told her (the consultant). She changed the tablets to stop the allergic reaction."(pt.19 - Accepter).

"I saw the doctor (chest clinic) she had told me she couldnot find anything. She said, 'it may be TB and as she wanted me to have all the tests'. She was very nice. I felt for first time, I found someone who listen to me properly....She did the skin test, it was on swelling measurements. I told her I had pain in my joint so may be I had bone TB . ..I gave my idea to her ...she started my treatment based on my condition" (pt.13 – Coercer).

4.2.3.6 *Plot six: Medical help and treatment care experience*

The treatment experiences of participants contain both positive and negative experiences of coping with side effects of treatment.

Subplot One: Side effects of TB Treatment

Several patients spoke about side-effects of the treatment and experiencing different bodily reactions.

"I got this bad itch all the time, burning my whole body. It was really bad. I had these aches, joint pain. ....I had steroids, it makes me angry. I was really nearly breaking down, mess up my mind ..." (pt.30- Tolerant).

"..I had Itching and sometime I had fever. I took paracetamol for fever ...they gave me information how to take tablets ..." (pt.14 - Sufferer).

"My head gets kind of hot and and my legs were itchy as well; so I am kind of used to it ...It is just like a lot better at the moment," (pt.17- Sufferer).

"I'm taking nine tablets a day. Itching sometimes but no other problems with the medication. .(pt.26 - Coercer).

For some patients the side-effects affecting their ability to walk and sleep well.

"the TB medication....was hell, it was hell, it was hell. The first week my legs were swollen and numb and very very heavy and sore ...I cannot lift my legs ...I cannot sleep ...At times, I felt like stop taking it. I was told I do not have to break it(stop taking it) ...So, I just keep taking it...." (pt.33 - Sufferer).

"I started feeling my joint very aching a lot, climbing the stairs was a problem. I was put on steroids my leg especially my knee joint was really paining ...if I sit for long I can't walk straight ....I explained to the doctor he said it was Ethambutol ..They stopped it I only had it for one week." (pt.36 - Doubter).

"When I first started the tablet... my body was itching me ...I was feeling dizzy then ...they told me ...if I feel something like that....I should let them know...I came back 'They stopped that' ...I have been using the rest." (pt.37 – Sufferer).

"when I started taking Rifampcin I used to have too much vomiting when I eat anything ...My ankle also started to swell, I cannot walk, I then called the nurse ...I told her the problem and they stopped that one and they gave me another one... that was good." (pt.27 - Coercer).

Sometimes treatment side-effects involve hearing problems, blurred vision.

"I had hearing problem and blurred vision. After the surgery in my spine....I am suffering from the pain .it is not easy... to walk, I use stick for walking... apart from that the treatment is working fine...the medication will continue 18 months to two years and I'm now using the second line of medication." (pt.32 - sufferer).

"My eyes were swollen ...it makes me put on weight they told me ...I started the drug. I eat everything... my weight has increased in two weeks by 10 KGs." (pt.20 - Doubter).

".... I used to feel headache, my head feels swollen and my face was swollen.... After three to four months of treatment and that was good result. ." (p24 - Accepter).

"Ten different tablets and they are all good. ...and I had no problem. I just had a pain in my body but they told me it was going to happen because of the medicine. They said, 'I had to stop the medicine' and they changed the medication'. I feel better, my elbow is fine my appeatite is fine, everything is fin." (pt.13 – Coercer).

Subplot Two: Getting better after treatment and had no side-effects with treatment

Equally, the narratives suggest that some patients were getting better after treatment almost quickly and some also had no side-effects from treatments. The experience of most of these patients has been quite positive.

"I am reacting to the medicines nicely. No side-effects. It went very well without any problrms. I'm feeling now absolutely great." (pt.28 - Sufferer).

"One thing what I feel, if your mentality and your thought is positive, anything whatever happening to you everything is going positively. No side-effects, ...I have one month to complete..." (pt.34 - Doubter).

"When I started taking the TB medication, in the first week I did not sweat at night anymore... it took some time for the cough to go. It took about a month to two months and the cough stopped." (pt.33 - Sufferer).

"I have got four months treatment left ...on the 16th of October, they said... 'The X-ray result was better than before, it is clearing just a little bit ...They have reduced the medication I'm taking only two instead of four tablets..." (pt.31 – Sufferer).

"I'm alright I don't cough anymore I have got another two months treatment left. After four months I started to feel normal. If I had to do it again, I would do it again and there is no problem I have no side effects." (pt.23 – Coercer).

"I feel much better now I take six tablets at six o'clock and I take seven tablets at eight O'clock and then I take two tablets at twelve o'clock. I have to take all these tablets to fix my problems or else I'll be in a hospital bed. I have got this problem, I have to fight it" (pt.18 – Tolerant).

"After starting to take the tablets the pain started to go away. I started to eat well, I had no side effect from TB medication." (pt.35 – Accepter).

"I limp when I walk because of my back. I see the effect of the medicine I do not feel any pain. My check ups took a long time and I've a bit of relief from the pain. I used to run like a boy but now I'm limp and can only walk with sticks for the next three months," (pt.22 – Doubter).

Subplot Three: Difficult to of cope with treatment and needed support

Difficulty of coping with treatment side-effects was mentioned by most patients. Narratives of four patients indicate that they had to rely on others and could not have coped with day to day living by themselves:

"I was told I have to start twenty eight tablets a day for the TB. ..... I was sleepy, drowsy could not do anything and could not get used to it. I could not look after children...." (pt.11 - Sufferer).

"In the first week ... I could not get out of my bed or do anything, I had to call my friend to get me somthing to eat. It was a very very bad experience..." (pt.33 – Sufferer).

"My friends are nurses.... They are close to me, they come and sleep in my house and also I was in a shared accommodation with them" (pt.36 – Tolerant).

"My friend always comes with me to the hospital. He supports me sometime. If I must cook I live in room upstairs so I needed to come downstairs to cook. It is difficult, that's why I needed to go back to Sri Lanka I feel very tired..." (pt.26 – Coercer).

Patient 24 and 27 spoke about how they found their doctors and nurses medical care.

"When I started the TB treatment every other day the nurse used to call me and asking 'how I was feeling and if there were any problems with me'. She is so good to me, she gave me confidence and told me, 'if I take my tablets everyday I'll be alright after six months'. She told me, 'if I have any problem to call her", (pt.27 – Coercer).

"I'm really happy with staff in this clinic ...they started my treatment. When I saw that doctor (chest physician), I was so happy, I felt I was alive again. ...he asked me why I was laughing. I told him, 'I got my medicine - I'm going to be alive again'. My kids are young, 'bursting in-to tears'. I am so happy, they gave me my medicine...and I'm feeling a lot better now." (pt.24 - Sufferer).

Patient 26 and patient 30 spoke about side-effects and support from their family.

"I'm taking nine tablets a day. I was itching sometimes but no other problems with the medication. Sometimes I could not walk my sister helped me when I needed to get up and walk to the toilet all that..." (pt.26 – Coercer).

"I got this bad itch everytime, burning all over my whole body. It was really bad. I had these aches and joint pain... I had steroids it makes me angry, I was really nearly breaking down, mess up my mind, I needed to be focused... I was in hospital for three weeks wanted to get home. I was offered care support with children, but I did not need it." (pt.30 - Tolerant).

Patient 13: spoke about her husband's support.

"I always like doing things as normal ...If my husband did not put pressure on me to go, I would have never been to the hospital. He forced me to go to the hospital and to take my treatments. He thought he was going to lose me..." (pt.13 – Coercer).

Patient 29 also described how his lack of family support has left him in a dilemma.

"I'm trying to go to Sri Lanka because there is no one here for me. Here sometimes I cook for myself. My parents told me to come back. I told the doctor here (chest clinic). He said, 'He cannot stop me, if I don't want to wait'. I'll try to stay for one month..." (pt.29 – Accepter)

Subplot Four: Treatment failure needed longer treatment

For three patients, their TB treatments were ineffective due to drug resistant TB
Patient 32:

"...I started the TB treatment (in Tanzania). ...I had the TB it has got some resistance to some of the medication, so the treatment will continue for 18 months or two years. I'm now using the second line of medication....That is the only comment I'd like to comment really." (pt.32 - Sufferer).

Patient 37:

"I have been on treatment for almost a year ...They told me, 'the first tablet they gave me if the tablet was working I would have only needed to take treatment for three to six months. The tablet was not working for my TB. That is why the time of the medication was is taking longer " (pt.37 - Sufferer).

Patient 39:

"With the TB, I am still sweating, weak ... I cannot sleep...losing weight, no apetitite. ...I do not feel any benefit from the tablets.... They (staff) said 'they are worried I may have drug

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resistant TB'. It may take one year if it does not cure it by six months they gave me the tablets, but I'm still vomiting." (pt.39 - Sufferer)

4.2.3.7 *Plot Seven: The ending of the story line: feeling thinking and reflection*

The ending of stories by participants contain positive feelings about the success of their treatment and for some, also remembering past events and recognizing the failure on the part of professionals to detect their illness early causing the disease to advance and affect them in many ways.

Subplot One: Feeling a lot better and happier about treatment outcome

Several patients spoke about how happier they felt with the medical and nursing care.
"I'm being a lot better, I can bend, I can walk and am a lot happier about myself." (pt.11 - Sufferer).

"I am happy ...every day I get back and say thanks to God I am still alive..." (pt.20 - Doubter).

"Before, when they told me I got TB, I thought I was going to die, but now I think I got new life....they gave me new life... I feel much better now." (pt.14 - Accepter).

"Now I'm feeling well, well ...and now I want to go back to my home country.... I want to change my mind and I want to be just like before what I am so." (pt.13 - Coercer).

Subplot Two: Felt much better after treatment

Most patients felt much better after starting treatment:
"Now today I'm feeling much better after seeing the doctor ... my second X-ray today ...looks much better ...and the doctor said the medication is suitable for the TB...." (pt.16 - Accepter).

"I can move my hand now ..., I can walk with the help of stick. They are helping me for the best. They said in twenty days time, I'll be discharged from the rehab ..." (pt.18 - Tolerant).

"I am really fine now. taking the medications, I responded so quickly even the doctors were amazed." (pt.36 - Tolerant).

"I moved from walking with the frame to walkng with two sticks - that is progress is in't it? I can't see what else is progress ...and I'm hoping everything works out for me." (pt.25 - Accepter).

"I'm fine and fit and I'm happy ...my medication will finish next month ....." (pt.34 - Doubter)

I feel very good. I've no cough, no pain, no nothing and am normal. (pt.27 - Coercer)

"I'm feeling absolutely great!" (pt.28 - Sufferer).

"I'm feeling better now ...My cough has gone. I sweat a little bit at night only. Some time some nights I'm OK....I'm a lot happier now with the treatment and everything." (pt.26 - Coercer).

"When I was keeping using the tablet, I was feeling better gradually...in two months...my breathing was normal, the pain gone down and the ... cough gone I feel better now." (pt.37 - Sufferer).

"Now I feel better. My weight also increased ...I sleep well ...The chest clinic staff are very good, they helping me, well, anytime I called them they helping me. " (pt.35 - Sufferer).

Some patients have noticed some improvements in their illness after taking TB treatments:

> "...I think sometimes I felt like blackout sort of thing ....apart from that, I see lots of improvement. I've got about four months treatment left to finish at the very least." (pt.17 - Sufferer).

> "... I'm a bit relieved with the pain but I'm still limping you know. I was a running boy but now I'm limping with stick now for three months now." (pt.22 - Doubter).

> "I feel much better. I'm not there yet. I'm not as I used to be. ... I've got to the stage I'm walking and now thanks to them, I'm recovered and ...wait more I'll recover." (pt.30 - Tolerant).

> "I feel OK ... just only the side effect I cannot complain about it ...they told me that if I had a problem I should let them know." (pt.33 - Sufferer).

> "The pain is still there, but becoming slowly not as strong as it used to be. The fever is going to stop ...I get some pain sometimes ... it is improving but not completely free of pain." (pt.40)

> "I feel a lot better and feel good, only the pain in the neck." (pt.41 - Accepter).

> "They X-ray they did was very good than when I started, but it is clearing just a little bit, they have reduced" (pt.31 - Sufferer).

Subplot Four: *Expressed concerns about the failure to diagnose early*

For some patients their stories also involved remembering events which led to delaying their treatment had been the reason for advancement of their TB illness and complications.

> "...if first time when I went to hospital they would have done test I'd have TB then not TB meningitis....I did not have headaches and the headaches come with meningitis. I do believe, if they had done more tests in more detail back then, I'd have needed treatment only for six months. I'd have not gone through this hell for twelve months.... That is what I think."(pt.30 - Tolerant).

> "They told me, 'I had TB meningitis' ...'TB has caused this lack of oxygen that caused the numbness'. ... I was a bit upset, you know. There was a bit of delay at the beginning... If they had started my treatment in the A&E, I would have not been in this condition.... ." (pt.18 - Tolerant).

> "...It is the referral always the system ...a long waiting list to see specialist so people like me who was diagnosed by the GP could not find the right diagnosis. The TB in the blood, it took three months for referral. By that time, the infection spread, I got worse...in my situation", (pt.32 - Sufferer).

> "I ...feel being let down by them ...in odd occasion - not getting right information to go right direction to deal with medical situation. The system needs improvements." (pt.11 – Sufferer).

> "When I saw my GP ...at that time inside me I wanted an X-ray and blood test but I was not confident enough to tell her what I wanted. I just kept quiet. If they have done the X-ray immeditaely at that time, they would have been able to detect TB, I would have not had problem with both lungs ..." (pt. 36 – Tolerant).

4.3   Results of narrative plots and subplots emplotment

The key findings from this analysis revealed what the participants conveyed in their core stories, deriving meaning from plots and subplots. This stage of analysis generated seven

generic plots: first healthcare contact experience; feelings and memories of medical consultations; referral pathways to diagnosis; undergoing TB diagnosis; medical help experience after diagnosis; medical help and treatment experience; story closure feeling and reflection. (see Table 12)

Within these seven plots, I was able to identify thirty subplots based upon the content of narrators' stories. The subplots contained content about the narrators' experiences that address the research question. Although each plot provides contextual understanding of narrators' experiences, the subplots deal more specifically with these experiences. The content of each subplot therefore articulates a specific answer to the research question pertaining to patients' pathways to diagnosis and treatment.

Table 12 Results of plots and subplots analysis 'emplotment'.

Research Question	Narrative Plots *Contexts of narrators' experiences*	Narrative Subplots *Content of Narrators' experiences*
What did patients say about their pathways to TB diagnosis and treatment?	First healthcare contact: choices experiences, and decisions	1. *Difficulty in getting registered or making appointment with a GP:* 2. *Personal choice or preference;* 3. *Convenience; urgency of consultation*
	First contact feelings and memories of medical consultations	1. *Telling everything about illness but being misunderstood* 2. *Being told to keep taking antibiotic that did not help:* 3. *Complaining the same problems: lost time on unhelpful treatment* 4. *Ignoring symptoms: testing for wrong thing*
	Medical help experience of pathways to TB diagnosis	1. *Immediate referral by GP* 2. *Referral after no response to treatment or critical illness* 3. *Referred on after critical illness* 4. *Putting pressure (transition to diagnosis)* 5. *Collapsed and taken to A&E while waiting after referral* 6. *Long wait after referral: never received a letter, had to make contact*
	Medical help experience while undergoing TB test procedures	1. *Complicated pathways of referral: long waiting before diagnosis* 2. *Undergoing long period of tests: no treatment, waiting in pain* 3. *Doubting TB diagnosis* 4. *I needed advocate support; had to beg; I had to fight for the test* 5. *Confusion over: medical opinion; tests; admission: (uncertainty)* 6. *Conflicting / changing / wrong medical opinion of chest X-ray result.*
	Medical help and admission care experience	1. *Not taken seriously for care need* 2. *Inadequate information and not knowing what was happening* 3. *Need for information adequately met*
	Medical help and treatment care experience	1. *Difficulty of coping with treatment and needed support* 2. *Treatment complications and drug resistance* 3. *TB Treatment side effect* 4. *Getting better after treatment and not having problems with medication*
	Horizons of ending story line feeling and thinking	1. *Expressed concerns about the failure to diagnose early* 2. *Feeling a lot better and happier about treatment outcome:* 3. *Felt much better after treatment* 4. *Noticing some improvements but not recovered*

4.4. Summary of the Chapter

In this chapter, I detailed the preliminary analysis concerning the length of time taken from patients' initial illness manifestations, healthcare contact, diagnosis, and the start TB treatment.

As Table 5 shows, the majority of patients sought healthcare within a month, and most of these patients were delayed for a considerable length of time before obtaining diagnosis and treatment. A key research question that this chapter sought to answer concerned identifying participants' experiences from the outset of their journey to seek medical help to the events leading to their diagnosis and treatment. The process undertaken in the development of core story experience portraits and five different experience portrayals were presented from the original thirty-two portrayals.

The identification of core story plots and subplots generated seven 'plots' and thirty 'subplots'. Through narrative plots and subplots emplotment (descriptive data analysis), what was told by participants key issues of were highlighted in each subplot with key quotes directly taken from narrators' accounts. As noted in Chapter 3, the primary aim of Chapter 4's analysis was descriptive (as described by the narrators) rather than analytic (thematic). In Chapter six, the 'plots' and 'subplots' found in this chapter are used to frame categories and themes of medical help in order to answer the third research question: what do patients say specifically about their experiences of professional help?

Throughout this chapter, five typologies highlighted in the experience portrayals are established, based on participant's quotations. Chapter 5 will present a holistic analysis of plot forms and types in order to understand how narrators told their stories about their pathways to diagnosis (induction of typologies). It will address the differences and commonalities of pathways to diagnosis by undertaking case-based analysis of the five experience portrayals presented in this chapter. Using five different narrators' pathways experience and each narrator's story for analysis, it will assess specific issues from the narrator's description of events (plot types) led to shorter or longer pathways. In so doing, the chapter will build on the findings of this chapter by looking more closely at each narrator's descriptions of their pathways and the events that shaped their experiences.

Chapter Five: Holistic Analysis of Plot Forms

5. Introduction

This chapter will present the rationale for analysing the pathways to TB diagnosis (particularly on relevant story plot types). In addition, it will discuss the process of inducting plot typologies. A case-centred analysis of five narrators' plot forms (*the five core story portrayals*) supplemented with data drawn from the remaining twenty-seven participants' story '*plot types*' will be presented. The plot '*typologies*' will be linked to the scholarly literature in order to perform an explanatory analysis of the plot types and events they refer to. The remaining chapter will highlight key findings in relation to the research question. The chapter closes by summarising the results and analyses presented thus far.

5.1   Holistic Analysis of plot form about pathways to diagnosis

The plot forms of narrators' pathways to diagnosis have been the focus of this chapter, in accordance with the second research question. As noted in Chapter 3, the structure of story plots by the storytellers reveals their experiences, which can be understood in terms of 'plot types'.

Q: How do patients tell the story of their experiences of pathways to the diagnosis?

Holistic form analysis is based on the work of Lieblich et al. (1998). The main assumption of the holistic form analytical model is that 'the formal aspects of structure, as much as content, express the identity, perceptions and values of the storyteller' (Lieblich et al.. 1998: p.88). Participants' forms of storytelling – narrative 'plots' –, vary in types (archetypal forms) or style of telling by each narrator, including the terms he/she wants to be interpreted' (Riessman, 1993: p.19).

As part of this holistic process, I read the narrative plots closely and identified 'focal' points that captured my attention or that '[rose] to the front of my mind' (Wright, 2009). The key point of interest was how participants described their experiences through words, phrases, and metaphors, which served to highlight key themes of their medical encounters. The close reading and immersion in the 'plot' about transition to diagnosis helped me to focus my analysis on plot types and to discern clues that revealed the participants' behaviours/actions in their medical encounters. In this section of the analysis, I have undertaken the following processes.

1.Recognising that each narrator's perspectives can be understood from plot types, I began my analysis with an attempt to understand each participant's story in its entirety in order to gain a global impression (Lieblich et al. 1998), focussing on the 'plot' about transition to diagnosis.

2. I then looked into Plot 3, 'medical help experience of pathways to TB diagnosis', by noting key expressions related to experiences that were unique to the teller's forms of telling. In so doing, reading the narratives closely, I was able to identify the salient points leading to holistic impressions of the story (Lieblich et al. 1998).

3. In reading each plot from the core story, it soon became obvious that most of the narrators' stories contained plots referring to different story plot forms at different stages of their pathways. For example, the narrators' stories contain different plot types referring to their transition to diagnosis compared with the plot types referring to their transition to treatment. My initial observation of differences in plot forms corroborates Polkinghorne's (1988: p.167) point that 'there is no single typology or system of categories to describe plots'.

4. However, it seemed that there was an exception to plot consistency, as some of the narrators' stories, particularly highlighted in the story plots of pt.19 (accepter) and the story plot of pt. 12 (doubter), where the plots typology remains consistent throughout their pathways to diagnosis and treatment (see Tables 6 and 8). A case-based analysis of these narrators' plots is included below.

5. Keeping my focus on the plot about transition of diagnosis, from the narrator's forms of telling, their actions, and the meaning conveyed in plot 3, I was able to observe five different behavioural patterns and actions in relation to narrators' experiences, as core story portrayals of pts.19, 21, 12, 23, and 38 indicates. A further discussion is provided in the case analysis of these narrators' stories.

6. Interestingly, in one narrator's story, pt. 39, the plot about transition to diagnosis was straddled between two different typologies (between coercer and sufferer) (see her portrayal in Annex 4, p.248 and two extracted quotes in Table 13 to illustrate this point). In order to understand this inconsistency, I looked further at the events leading to the use of particular expressions and the events occurring afterwards. I also looked into the similarities and differences between experiences in relation to other narrators' (in the sufferers and coercers group) description of events. By doing so, I was able to identify reasons why the plot types of the narrator highlight more on suffering rather than coercing, as Table 13 illustrates.

7. Identifying consistent plot types and those that were straddled between two forms of expressions offered further insight into the events underpinning changes in narrators' plot type patterns. Narrators' forms of expression appeared to be related to events and the type of communication they experienced with professionals during medical encounters (see Table 13).

8.Having checked events before and after transition to pathways to diagnosis and then comparing similarities and differences with other narrators' descriptions, I was able to form a subjective evaluation of the typology that matched each narrator's plot forms in terms of meaning, behaviours, actions displayed, and events experienced.

9. A graphical holistic-form representation of each narrator's journeys also helped to interpret each narrator's pathway to TB diagnosis and treatment. Particular attention was paid to the time and place of each participant's experiences and the 'foci' of the story teller's descriptions of his/her pathways was plotted.

10. In these steps, I was able to classify the participants' forms of telling according to the characteristics of the 'self'. Moreover, their patterns of behaviour and actions allowed me to classify them into the following groups: accepter, sufferer, doubter, coercer, and tolerant, where each core story portrayal highlights key expressions from the story (see Tables 6, 7, 8, 9, and 10). I identified the forms of professionals' responses that evoked these

behaviours, including *attending, ignoring, limiting* and *switching, and adaptive and maladaptive stress responses.* (discussed in more detail in section 5.2)

Table 13 presents the research question and 27 participants' extracts containing key expressions, which highlight the plot types characterised from stories about their pathways to diagnosis

Table 13 Narrative typologies from participants' stories

How did the narrators tell about their pathways to the diagnosis?	Plot types/ Forms	Character of plot Typology
... I was in agony finally I could not walk... the lump on my back was growing the size of tennis ball ... (pt. 11)	Sufferer	Consistent
..... I had fight with them may be two or three times. .....had to fight for test.... (pt.13)	Coercer	Consistent
.... I told her, (new GP) that, 'I want to go for chest X-ray'....(pt. 14)	Coercer	Consistent
...the specialist and my GP are actually very supportive I have to say... (pt. 15)	Accepter	Consistent
....my journey was short ...as far as I am concerned I should say I was lucky.(pt. 16)	Accepter	Consistent
.....started going back backwards again ....could not get GP to refer me... my health getting worse....(pt.17	Sufferer	Consistent
...So I said, 'ok no problem...I needed to be calm and be patient... (pt 18)	Tolerant	Consistent
... I do not think there is a need for GP ... never ever diagnose the problem ... I do not think I have TB ...because ...they did the mantoux test ....'what about you put the needle in wrong way ...That's why ...the measurement was so big....(pt. 20)	Doubter	Consistent
......after one year they told me I had TB why ...I think I cannot believe it ... (pt. 22)	Doubter	Consistent
... I told my GP ... the pain in my tummy... my back I was suffering a lot... (pt 24)	Sufferer	Consistent
.... If it wasn't for them (professionals) I would have not been here .... (pt.25)	Accepter	Consistent
...if I left it for him (go along with the GP's opinion)... I may have not gone for an X-ray.... (pt26)	Coercer	Consistent
..... I told him, 'I need an X-ray' he said I can go only when it's a problem. (pt.27)	Coercer	Consistent
....unless you collapse in hospital and join emergency ...that was my very bad experience...(pt. 28)	Sufferer	Consistent
...the GP send me to Middlesex hospital. ...they're all good and the GP is also alright... Pt. 29	Accepter	Consistent
... I had all similar symptoms not much different .... I just carried on like this for another month...(pt. 30)	Tolerant	Consistent
... losing weight, coughing a lot he (GP) did not know what was wrong with me. (pt. 31)	Sufferer	Consistent
.....The doctor misunderstands me I am suffering from TB.... (pt 32)	Sufferer	Consistent
......they said my chest is clear ...they do not know what was actually happening to me...(pt. 33)	Sufferer	Consistent
....the GP said it might be TB I cannot accept it there was no wrong with me.... (pt.34)	Doubter	Consistent
... I could not see the GP....they said I should go to A&E ...I was then taken to the hospital... (pt. 35)	Accepter	Consistent
...I was not confident enough to tell (GP)...I rather not keep quiet but I kept quiet .... (pt. 36)	Tolerant	Consistent
...I kept telling them that this pain is getting worse..... (pt.37)	Sufferer	Consistent
I put pressure on my GP to do something...., ...'why they let me suffer ... you see how much I suffer from all these... ...' (pt. 39)	Sufferer	Straddled from coercing to suffering
... the fourth time I insisted he should referred me to the hospital....(pt. 40)	Coercer	Consistent
....They were helpful and everything was fine everything is alright for me and no problem....(pt.41)	Accepter	Consistent
... everyone was good to me... (pt. 42)	Accepter	Consistent

Tab 14 Narrative plot types and medical help experiences

Narrative plot Typologies	Meanings derived from behaviours, actions displayed in narrator's plot structure (forms)
Accepter	Is a story teller who tells about his/her medical help and opportunity for diagnosis and treatment as a positive experience and he/she did not recount any specific concern about his/her medical help.
Sufferer	Is a story told by a teller who expressed about his/her suffering a lot and had difficulties in obtaining appropriate medical care and drifted into critical condition before obtaining TB diagnosis and treatment
Coercer	Is a story told by a teller who has told about how he/she needed to put pressure on healthcare professionals in order to obtain medical care he/she needed
Doubter	Is a story told by a teller who doubted about his/her medical help or his/her TB diagnosis but he/she fully cooperates with his/her treatment and care in order to get better.
Tolerant	Is a story told by a teller who appears to have a tolerant attitude to events he/she has gone through during his/her medical care. The story signifies how he/she handled situation to get on with his/her medical help and regrets about events that had led to his/her bad experiences.
Medical help communication experiences	**Medical Assistance in relation to patients' narratives**
Attending	In this research the classification typologies achieved from narrator's plot(s) expressions and descriptions of events leading to TB diagnosis that typify the medical encounter as **attending'** to the patient's clues and asking the patient to describe and take appropriate action on what is needed for the patients.
Limiting	Is a story teller who tells about his/her medical help and opportunity for diagnosis and treatment which was a difficult experience as his/her encounters involved his/her specific concerns about his/her medical help not being taken into consideration and the doctor's response to his/her concerns **'limiting'** his/her ability to explain his specific worries/concerns.
Ignoring	Is a story told by a teller who has told about how his/her medical encounter involved telling her/his doctor everything about what he/she needed but the response **'ignored'** the specific issue of what the patient worried about.
Switching	Is a story told by a teller who has told about her/his medical encounters involved telling her/his doctor everything but the response was 'Switching' which means **'not attending to patient's cues'** instead of why the medication has not worked.

The table above presents the plot types and constitutive definitions and also the contexts of medical help experiences that triggered the narrators' forms of telling are defined. The section below will present a case-based analysis of the five narrators' portrayals using Table 14 as schemes of reference to aid my representation of the narrators' experiences.

_____

5.1.1 Case 1: Patient 19 (accepter)

The story of the non-English speaking patient 19, **(see Table 6)** is chosen to represent the group of patients' experiences of pathways to diagnosis and treatment. The patient described the first contact, how her GP did not offer her treatment but she (GP) wanted to investigate her concerns by referring to the chest clinic directly. Despite her (the patient) feeling unhappy about the lack of treatment by the GP, after waiting for the chest X-ray

results, her needs for diagnosis and treatment has been followed up by the chest physician. She spoke about how her TB treatment was effective on reducing her illness symptoms she had experienced and that was continued to the end of her treatment completion and full recovery.

The story did not highlight any significant problems, nor does it describe any specific challenges that she needed to tackle in order to recover fully. She spoke about how her recognition of the threats, seeking care early and obtaining the help she needed. Her story depicts her survival strategy as one of being '*accepter*' in order to achieve full recovery. The story told also appeared to signify medical help from her doctor who was "*attending*", (definition in Table14 above) because her description of the communication with her doctor gives a positive experience as the doctor's action based on understanding of patient's clinical history and urgent referral to chest physician. According to Del Piccolo et al. (2011) the doctor who empathises; acknowledges; and explores illness and takes action which patient was complaining about is likely to gain the patient's acceptance. Fig 11 is a graphical diagram showing her journey to diagnosis and treatment.

Fig 11: Patient 19's experience of pathways to diagnosis and treatment
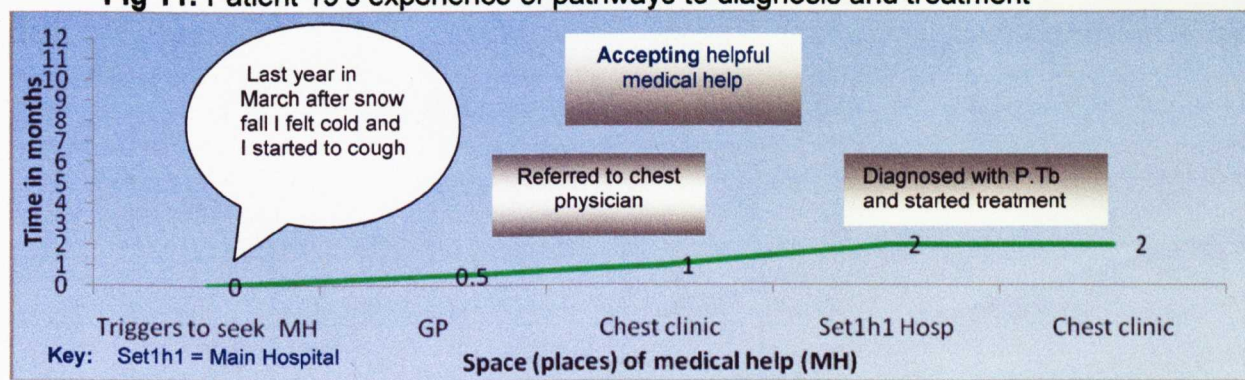
5.1.2   Case 2:   Patient 21 (sufferer)

The second story **(Table 7)** is of a male pulmonary TB patient who contacted the local WC and described his experience of medical help involving suffering for three months. The story teller described how his contacts with WC involved numerous tests that did not identify TB and then referred him to the diabetic service at Set2h2 Hospital. He spoke about the doctor who referred him to the Set2h2 but did not mention his chest problem and, while waiting for referral, he was unable to obtain any treatment which he found a very "upsetting" experience.

After referral, he spoke about how worried he was about the time taken at the S21 hospital while waiting and suffering without treatment. His story also reveals that when he

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returned from a visit to hospital and was sitting at home not knowing what to do, he received a phone call from a chest physician in which he (the patient) had no knowledge of how he was referred to the chest clinic. His suffering then appeared to change after he had seen the chest physician who had cancelled all his appointments with the Set2h2 hospital to start his TB treatment. He links his suffering to poor understanding of his real concerns and not undertaking the right tests he needed. The story illustrates how the pathways to diagnosis and treatment involve suffering due to misdiagnosis and confused referral pathways by primary care physician in the WC. The account of this patient experience of medical help also appeared to signify medical help in WC by a doctor who was *'ignorer'* (see definition in Table14 above) because the story by the teller highlighted how his illness symptoms and suffering was Ignored by the doctor. Furthermore, the story also reveals how the patient's complaints were dealt by his doctor who paid emphasis on routine non TB specific tests and he made no attempt to respond to his real expressed concerns and which led to him being referred to diabetic specialist at the Set2h2. Suffering is the focus of the story and the plot describes his actions and the behaviour he displayed in response to medical help provided by the doctor in WC. Figure 12 below shows his journey to diagnosis and treatment.

Fig 12: Patient 21's experience of pathways to diagnosis and treatment
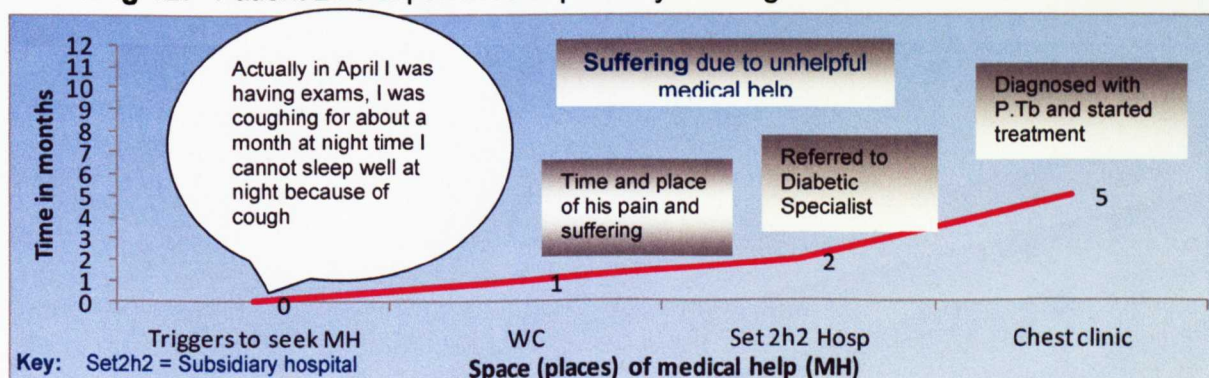
5.1.3   Case 3:   Patient 23 (coercer)

Unlike the story of patient 21, **(see Table 9)** the story of patient 23 denotes the story of some patients who experienced difficulty in obtaining medical help that meets their needs and subsequently led them to put pressure to obtain help they needed. He describes that despite numerous contacts and antibiotic treatment offered to him, he was unable to see improvement in his illness. His GP's never ending offer of antibiotics has led him to demand

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a chest X-ray referral. He has also said that he knows that he had to tell his GP that he did not want anymore antibiotics in his own words he had "put pressure" to get through the system in order to obtain referral he desperately needed from his GP. The patient description of his medical help experience from his GP, particularly his description of the consultation typifies a *'ignoring'* (see definition in Table 14 above) particularly to his concerns about the antibiotic treatment and his illness. The story teller experience typifies a medical help by a GP who provided a limited opportunity for him (the patient) to tell his doctor about his illness experiences.

From the story teller's experience the GP first thought the patient's illness was not serious and required paracetamol and then antibiotics in a number of contacts; this seemed to necessitate the patient to put pressure on his GP to refer him to Set1h1 hospital for an X-ray. (see core story plot 2) Putting pressure on his GP is the plot describes his survival strategy as the focus of the story. Fig13 indicates his journey to diagnosis and treatment.

Figure 13: Patient 23's experience of pathways to diagnosis and treatment
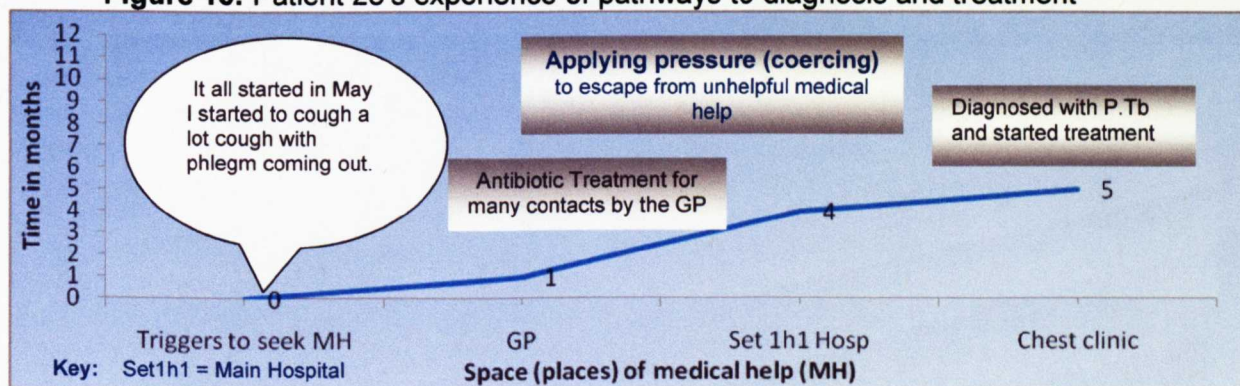
5.1.4   Case 4:   Patient 12 (doubter)

'Doubter' is the story (see **Table 8**) of a type of a patient who has found that the medical help from her GP necessitated numerous contacts, tests and treatments offered to her for asthma which she found intolerable. She spoke about how she had to let her GP know that the treatment given to her was not the right treatment. Her referral for asthma tests was unproductive and she explained that she was unable to perform the tests and, eventually, she decided to seek emergency medical help from the A&E by herself. The storyteller's experience also suggests that the medical help from her GP typifies not attending to her cues – meaning that despite her telling the GP about the symptoms of her illness, the GP

assumed that her illness was related to asthma and did not attend to the patient's concerns and cues.

She doubted the relevance of the treatment and tests offered by the GP and sought help from the A&E. She spoke about the A&E doctor, who suspected TB based on her presenting symptoms and the results of her X-ray. She also spoke about how the subsequent tests were unable to reveal her TB and this resulted in delaying the treatment she needed. When she began her journey to the A&E, she was aware of the problem associated with the medical help she was getting from her GP. She did not anticipate any difficulty associated with hospital care. Her admission was an uncomfortable one and she found that the isolation unit experience exacerbated her suffering. This led her to discharge herself from the hospital. She also talked about how the treatment was delayed by the lack of confirmatory tests and that a chest physician had to make a decision based on her symptoms. She also doubted the appropriateness of the doctor's decision when she began her treatment

She believes that many patients like her suffer while seeking medical help from their GPs and that seemed to have led her decision not to see her GP anymore. She also spoke about the chest physician who acted in her best interest by beginning her treatment which made significant improvement after treatment. This and other issues of what the patient had talked about seems to illustrate how the story teller narrated her experiences of doubt throughout her journey in a unique way that gives a holistic impression. Doubting is the focus of the story and the plots describe her actions and the behaviour she displayed in response to medical help provided by the GP and while in hospital care. Fig 14 indicates her journey to diagnosis and treatment.

Fig 14: Patient 12's experience of pathways to diagnosis and treatment


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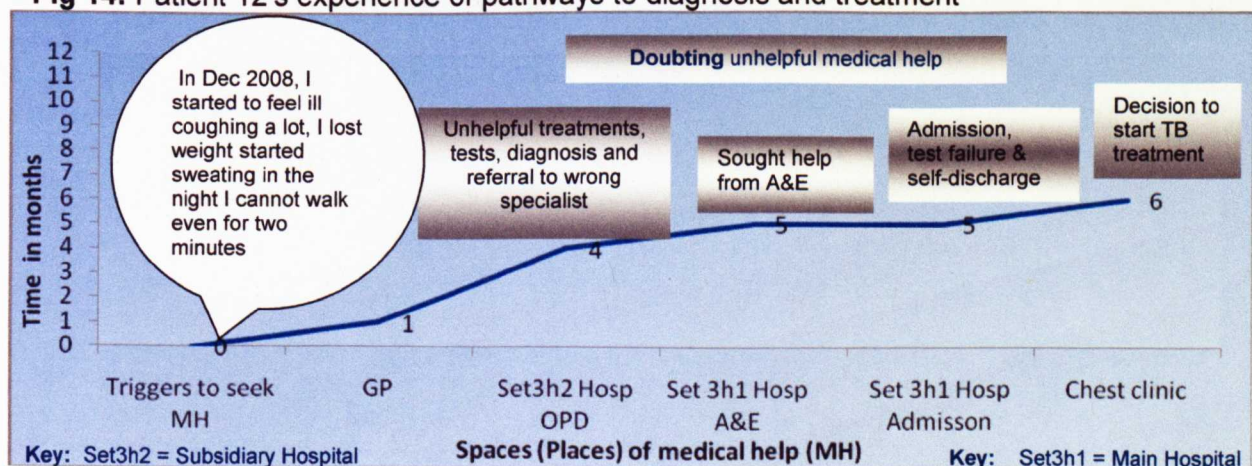
5.1.5 Case 5:   Patient 38 (tolerant)

The story from UK born patient 38 **(see Table 10)** with P.Tb indicates that as she related, her tolerant nature in many ways contributed to her experiences of many months' treatment for pneumonia by her GP and severe complication of her illness and led to loss of left lung and treatment for extra multi-drug resistant TB. She describes herself how her illness started as a seasonal viral illness for which she took pain killers for about a month before contacting her GP. She spoke about how her GP mis-diagnosed her illness and misinterpreted her chest X-ray the reason for her TB becoming untreatable. She felt it was hard for her to think of any wrong doing on her part in the causes of her traumatic experience of her illness. Her story also reveals that despite the fact that it was known that her TB was infectious and MDRTB, she had to wait for nearly three months at home due to lack of room (what seems to refer to negative pressure facilities) before the new treatment began in July. On the one hand I found her story is rather shocking for me as listener. On the other hand, her ability to articulate her story in an emotionally balanced way signifies how tolerant (cooperative) she was with professionals, despite having gone through such traumatic experiences. The story also depicts how she trusted and had a belief in the medical help provided by her GP by being tolerant at the time of her suffering.

The story seems to signify medical help by a GP that is *'Limiting'* elaboration on cues. The meaning of this is that, although her GP appeared to be concerned about her lack of response to antibiotics as her story seems to imply, the GP did not attempt to explore further the patient's illness symptoms or other possibilities at the crucial stage of her need for referral and key tests. As she told the story, the GP's response to her not getting better was advising her to take additional course of antibiotics.

Fig 15: Patient 38's experience of pathways to diagnosis and treatment

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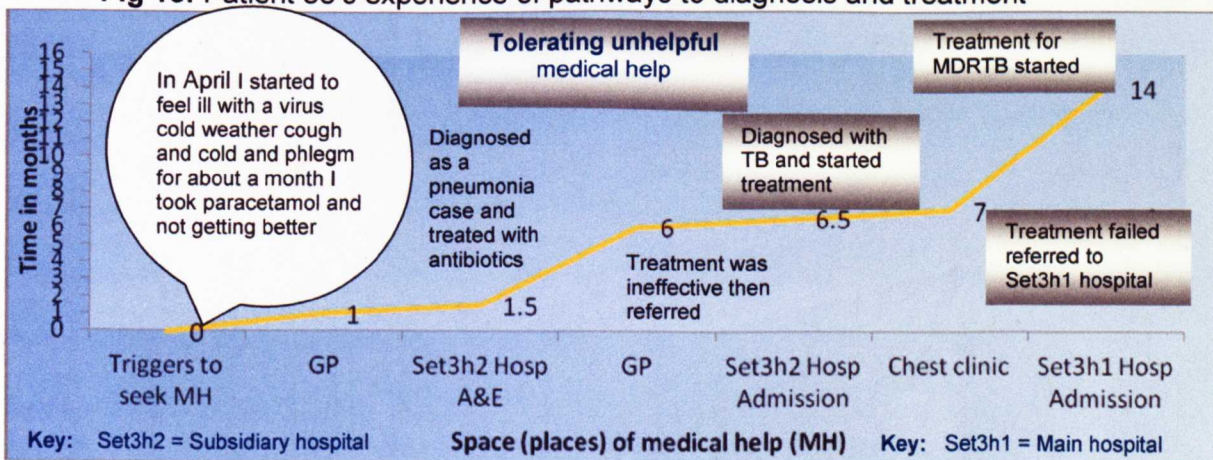
She also spoke about how her tolerant attitude towards her GP's care in part also led to her traumatic experience of her illness, as she did not put pressure on her GP to refer her to specialist care. Being tolerant is the focus of her story that signifies the behaviour she displayed in response to medical help provided by her GP. Figure 15 above shows her journey to diagnosis and treatment.

I have found Valent's survival strategies (SSs) and Del Piccollo's doctor-patient communication coding schemes useful for the case based holistic analysis of plot forms. The section that follows will discuss these schemes of references in order to explain the typologies inducted in this research. .

5.2 Holistic analytic explanation of 'plot types'

The five narrative plot forms (typologies) which were inducted from the data are related to the concept of survival strategies (SSs) proposed by Valent (1998) and the four doctor-patient communication coding schemes proposed by Del Piccolo et al. (2008). Firstly, Valent (1998) states that the concept of SSs can be used to facilitate an individual's recognition, naming and sense making of a varied sequence of traumatic events. His categorisation of eight dimensions of basic SSs and appraisals of them include: competitor (*must obtain the essentials*); fleer (*must move away from danger*); rescuer (*must rescue others*); fighter (*must remove danger*); co-operator (*must create scarce essentials*); attaché (*must be rescued by others*); asserter (*must achieve goals*) and adapter (*must surrender goals*). According to Valent SSs are specific stress responses which include specific adaptive and maladaptive states of: biological (*arousal, opioids, testosterone, cortisol*), psychological (*defeat/grieve/envy, phobia/panic, abandonment, betrayal*) and social (cry/insecure / separation, turn to new, disintegration/disconnected, avoidance/panic, oppression / struggle / plunder responses.

Looking at the plot types in accordance with Valent's (1998) concept of SSs and particularly the appraisals that evoke the various types, resulted in the following analysis: the figure of the competitor is close to what the "*coercers*" saw as being essential for their needs; fleers, to some extent, can be found in some "*doubters*" descriptions of doubting medical help, which led to them finding an escape from unhelpful encounters; the co-operator appears to correspond to the "*tolerant*" patients' cooperative natures; the attaché *(rescued by others)* figure seemed to be the counterpart to "*sufferers*" descriptions of how they had to be rescued in the end, and the adapter figure correlates with the "*accepters*" whose goal of attaining medical help from skilled professionals was fulfilled.

Secondly, the medical encounters (*doctor-patient communication*) in the narrators' descriptions of their experiences also appeared to relate to the four doctor-patient communication coding schemes proposed by Del Piccolo et al. 2008 – (cited in Atherton et al. 2009). According to these authors, this scheme for defining patients' cues/concerns and doctors' responses can be applied in two stages. This coding scheme defines a 'cue' as a verbal hint from the patient suggesting unpleasant feelings, pain, emotions during medical encounter. The coding scheme defines the doctor's response to the patient's worries as: *'inviting explicit affect'*, which entails **'attending'**; an *'inviting non-explicit back channel'* means **'limits elaboration'**. A *'non-inviting non-explicit'* response refers to **'ignoring'**; A *'non-inviting explicit switching'* means changing the flow of communication and **'not attending'** to the patient (Del Piccolo et al. 2011:p.151-3).

5.3   Results of Holistic Analysis of Plot Forms

The key findings from this analysis were that the narrators' forms of telling used five archetypal forms or typologies: coercer; tolerant; sufferer; doubter; and accepter. As noted above, in five case-based analyses of each patient's encounters that led to particular behaviours and actions they stories revealed certain themes of medical help: *attending, ignoring, limiting,* and *switching.* The five cases pathways represented in Figures 11,12,13,14, and 15 provide graphical illustrations of each participant's pathways to diagnosis and treatment. The time-length analysis of the five cases showed differences between the shortest, the acceptor (flatter) and the longest, the tolerant (steeper), who delayed longer before diagnosis.

The transition to diagnosis (referral pathways) for the sufferer involved a long period of treatment and being critically ill with TB. Similarly, the tolerant, doubter, coercer patients were also referred after lengthy and ineffective treatments. However, the acceptor narrator pt. 19 was referred quickly by her doctor. During diagnosis, however, the doubter pt.12 had experienced delay in obtaining medical help. The referral pathways for the coercer pt.23 involved pushing for a referral. Looking at the time length analysis by typologies there seemed unlikely to be any similarities within group experiences. The analysis of the length of time for medical help according to narrative typologies does not clearly show the commonalities or differences between the groups. From Fig 10 in pg. 86, it can be seen that the time length generated data did not prove to be more valid indicator on its own to reveal patients' experiences. The colour coded plot lines. indicating: red (sufferers), green (accepters), yellow/amber (tolerant), light-blue (coercers) and dark-blue for (doubters). However, longer delays were more common in the sufferers group, and the shortest delay

was found in the accepters group. An analysis of typologies using graphical forms would need to be treated with caution because the holistic form of analysis is usually linked to the narrators' forms of storytelling as found in plots and related to the narrators expressions/behaviours and action they displayed. Each narrator's experience of time in relation to his/her medical help may not have been captured from his/her expressions. This is because the severity of TB and the survival strategy (SS) employed may be unique to each person's situation. This may have been the reason why some of the narrators suffered for a shorter length of time while others suffered over a much longer time period.

The key conclusion that I have drawn from this analysis is that based on these results, the length of time taken to examine patients before diagnosis on its own does not cover the extent of the patients' experiences. The result showed how each individual has a unique survival strategy to tolerate, fight or suffer, and can be doubtful about events when needing help for an illness as a result of his/her experiences.

5.4   Summary of Holistic Plot form Analysis

In this Chapter, I have presented information as to how I have conducted analysis in order to answer the question outlined above. My aim was to understand how narrators construct their stories using the holistic form of narrative analysis suggested by Lieblich et al. (1998). I present the textual and graphical material, and also the results and analysis I have carried out in order to gain a more holistic understanding of the key research question which I sought to answer.

The choice to induct narrative typologies from the data (theorizing from a case), rather than using the favoured typologies was based on the key premise of narrative enquiry, Riessman, (2008:p.74) as discussed in section 3.3, p.63. I recognise that the readers' interpretations may also differ from what I have presented here, as the assumption in this thesis is that there is no one way of looking at things, including the stories above, as there are multiple perspectives of reality which lead to the many ways in which we interpret things. Stage two (in this Chapter) of the analysis process served several purposes:

1. Looking at the participants' experiences in relation to the typologies helped me to look beyond the content of what they said and to see how their story was told in relation to the context which gave rise to the formation of meaning the behaviour/action displayed and the type of medical help experienced.

2. The data were arranged in order to examine the typologies of all of the participants' narratives (the 32 experience portrayals). Key words, phrases and expressions that were related to the five typologies were 'cut and pasted' and presented in the form of

'quotations' in order to support the typologies (see quotations in the five experience portrayals and also in Table 13 for the remaining patients).

3. The descriptive data were sorted into manageable analytical categories of medical help that proved useful in understanding the salient points of experiences of medical help, for later thematic induction.

4. Thus, the typologies helped me to move into the subsequent thematic analysis by enabling me to shift from an understanding of meaning, derived from the narrative interpersonal function of how it was conveyed, to an understanding of the similarities and differences between individuals and hence to the identification of commonalities between the narratives that might be used analytically (Wright, 2009).

In Chapter Six I have gone through the data in more depth in order to look into the textual function (meaning) of what was said about experiences of receiving medical help from professionals, with the analytic emphasis on induction of categories and themes.

Chapter Six: Categorical Content Results and Analysis

6. Introduction

This chapter will present the analysis of the participants' core stories presented in Chapter 4 using a categorical thematic approach. The holistic analysis of five narrators' plot types also explored events that the five narrators' described concerning their communication with their doctors. Their doctors' responses/actions to the patients' need for referral were varied. One patient's need was effectively 'attended to', but the remaining four patients were either not encouraged to 'express their need' or were 'ignored'. Also, the doctor's response did not address the patient's real worries.

The aim of this chapter is to further derive *'textual meaning'* from specific issues contained in the six *'plots'* and *'subplots'* in order to induct categories of medical help and specific themes contained in them. Results are presented with reference to the third research question posed below. The process of thematic induction from each subplot will be achieved by analysing (quotation) referring to specific medical help experiences. Themes derived from subplots will be linked to theoretical schemes to highlight their explanatory value for participants' medical help experiences.

6.1   Categorical Content Analysis of 'plots' and 'subplots'

This section discusses the categorical thematic analysis of 'plots' and 'subplots'. As noted in Chapter 3, the 'selection of subtext' of narrative data from each 'plot' and 'subplots' of narrators' pathways to diagnosis are analysed in order to answer the third research question.

Question 3: What did patients say specifically about their experiences of medical help from professionals?

The key question that required addressing here was: what are the specific issues contained in the narrators' textual data (plots and subplots) words, phrases, and metaphors that may help to identify themes related to specific medical encounters?

In this section of the analysis:

1. The temporality of the core story plots and subplots was explored, focussing on the times and locations of experiences. In doing so, it became clear that the pathways to diagnosis and treatment broadly involved three stages in a continuum: *'before diagnosis'*; *'during diagnosis'*, and *'after diagnosis, including treatment'* using these key stages of pathways helped to arrange plots and subplots in a sequence, by linking them to the times and places of the participants' experiences. (see Table 15 below).

2. The analysis in this section explores the six plots and 30 subplots in terms of specific "plot content" from textual data on medical encounters. Each plot is related to a 'category of medical help' and each "subplot" is analysed thematically, inducting themes contained therein.

3. The close reading of texts' "plot" and "subplots" for content and contextual details provides further insight into the specific medical help participants experienced in their medical encounters. I was able to classify the six plots' contents according to the type of medical help they refer to, in order to categorise them into the following groups: *consultation; referral; tests; information, care support; treatment and feelings* about medical help. (see Table 15 below)

4. The process of identifying six categories of medical help helped to arrange "subplots" found in Table 6 according to the categories of medical help. Using this category of medical help, each "subplot" and the theme that it contains was brought together in order to highlight the categorical themes. (see Table 15)

5. To summarize, the story plots were linked to the categories of medical help, and the subplots (containing specific themes) were arranged according to each category in order to formulate the picture of participants' *'content universe'*, Lieblich et al. (1998:p.112-4) which I have interpreted as referring to the phenomenon of medical help (encounters).

In Table 15 below, the main questions and six "story plots" identified in stage one analysis are linked to six categories of medical help. Key "subplots" identified in Chapter 4 and specific themes contained therein are indicated in bold to highlight the themes inducted in the process.

Table 15 Narrative plots and subplots by categorical themes

Research questions	Core-story Plots	Category of medical help inducted	Core-story Subplots	Themes inducted
Before diagnosis what do patients say about their experience of medical help from health care professionals?	First contact feelings and memories of medical consultations	1. Consultation	I told him/her everything not listened to: He/She was thinking something else: He/she had said other things: Was kept on antibiotic does not help; I lost time on painkillers for long time	**Being misunderstood Misinterpretations of TB symptoms & misdiagnosis** **Kept on in-effective treatment for long time**
	Medical help experience of pathways to TB diagnosis	2. Referral	Quickly referred: Referral after antibiotics failed: Referred when I was in agony: Putting pressure to refer me: Went to the A&E:	**Referred quickly (High TB suspicion) After no benefits from the treatment when only critically ill After pushing for referral Sught help from A&E (Self referral)**
During diagnosis what do patients say about their experience of medical help from health care professionals?	Medical help experience while undergoing TB test procedures	3. Information	Waiting too long after referral: Not been informed:	**Miscommunication after referral) (Inadequate information)**
		4. Tests	I needed: advocate; to beg; or fight for test: Complicated pathways to TB diagnosi Uncertainty of diagnosis Doubting diagnosis:	**Applying pressure (pushing) for test** **Being misclassified Test failure – Assuming not TB. Doubting, & denial of TB diagnosis**
	Medical help and admission care experience	5. Care & support	Ignoring my symptoms & conflicting medical opinion of my illnessss. Not taken seriously	**Felt ignored and had no sympathy Lack of supporting care**
After diagnosis and during treatment phase what do patients say about their experience of medical help from health care professionals?	Medical help and treatment care experience	6. Treatment	Felt listened to, well supported and quick treatment: Needing longer treatment No side effects only benefits: Needed family/friends support and seeing improvement:	**Felt listened and cared for Quickly began my treatment Felt better after treatme & no side-effects Felt better with some side-effects Needed longer treatment**
How do they end their stories?	Horizons of ending story line feeling and thinking	7. Feelings about medical care	Happier, hopeful and better feelings about recovery. Regret about the consequence of failure to diagnose early:	**Treatment success** **Memorising experiences of inappropriate medical help and failures**

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6.2 Categorical Content Analysis: *Induction of Categories and Themes of medical help*

In this section, I will present the categorical thematic analysis in three stages. In Section 6.2.1 Pre-diagnostic medical help, In Section 6.2.2 Diagnostic medical help and in Section 6.2.3 Treatment phase of medical help. In each stage, relevant subplots from Chapter 4 will be analyzed thematically. Finally, key themes inducted in three stages of analysis will be linked to the doctor-patient communication models to assemble together various themes across the participants groups in order to answer the third research question.

In order to avoid duplicating the quotations, the plots and subplots containing themes were extracted directly from five experience portrayals (core stories Table 6, 7, 8, 9 and 10). In the analysis of each theme, the relevant quotations which contained the theme were copied and pasted from portrayals directly for analysis. However, where the theme was absent from the five experience portrayals, quotations needed to be brought forward from stage one for categorical thematic analysis. Few of the quotations from the experience portrayals were used in this stage of analysis in order to avoid the unnecessary duplication of materials already presented in the portrayals.

The quotations were taken mainly from the relevant plots found in the five experience portrayals in order to make the analysis process more transparent. I paid attention to ensuring that the content and context of each narrative remained intact for my interpretive purposes (Riessman, 2008). The induction of themes involved key phrases, words and expressions found in the subplots, identified from the *data (first order construct)*. The analysis was focussed more specifically on what the participants said about their support from professionals rather than using key reference material from the literature. At each stage of medical help, the patients' experiences and themes were found to include either positive or negative experiences from their stories.

6.2.1   Pre-diagnostic medical help

Category 1:   Consultation

In the category of consultation in the pre-diagnostic stage, participants spoke about their experiences of medical help which involved not being listened to or being diagnosed with conditions that they felt were unrelated to the illness they were experiencing (misdiagnosis).

Theme 1:   I told him/her everything but was not listened to: (being misunderstood)

The major theme, that of *'being misunderstood'*, was found consistently in Plot 2 and Subplots 1-4 and suggests that despite patients telling their clinicians the symptoms they

were experiencing, they felt that the communication process was often unproductive and that their doctors were not on the same page.

> "I lost weight, I started to sweat in the night, I cannot walk even for two minutes ...I told my GP how I was feeling. When I was telling him I cannot breath he was thinking I had asthma ... That was what he was thinking, I am asthmatic but 'I told him everything. The GPs sometime they do not understand you'...". (pt.12 – Doubter, Core Story – Plot)

> "I lost nearly a couple of months going back and forth to the GP. The GP was thinking something else she told me it might be cancer. The blood test shows nothing ..." (pt.32 - Sufferer)

The expression: 'I told him/her everything, but he/she thought differently', was present in a number of encounters, and may clarify the various forms of miscommunication in the interpretation of symptoms which patients experienced. These extracts above from the accounts of two patients highlight this theme. It is important to note that each quote from these patients the doctors' responses were not attending to their cues.

Theme 2:   Symptoms were not thought to be TB: (misinterpretation of symptoms)

In the category of consultation, the theme of 'misinterpretation of symptoms' was found in the accounts of 21 patients' medical consultations during the pre-diagnostic stage of medical help. Most of these patients spoke about their experiences of taking either antibiotics or pain relief medication including pain killers for a considerable length of time which involved many periods of contact with their doctors.

> "I felt ill started with severe cold, coughed a lot with phlegm and fever. The GP gave me antibiotics after I had an X-ray he suspected pneumonia. He said, 'I should take antibiotics for three months'." (pt.38 – Tolerant Core Story – Plot)

> "'I was having temperatures'. He said, I should have some rest and take some paracetamol'. I then started to vomit, vomiting fresh blood. I phoned him and told him, 'I am vointing blood'. He said 'no because I'm trying to vomit'. ...I had all this flu like symptoms: aches on my body, temperature. They thought it was Swine flu, they gave me relenza at home and I had that for three days." (pt.30 – Tolerant)

The extracts above illustrate the context of communication between doctors and patients during consultation. These specific issues that characterise either the mis-diagnosis or the misinterpretation of symptoms are the underlying features of miscommunication during consultation.   For the two participants, the theme of misinterpretation of symptoms partly expressed in the form of their doctors' diagnosis and treatments offered to them.

Theme 3:   Kept on unhelpful antibiotics: (cycle of ineffective antibiotics)

The theme of cycle of ineffective treatment was found in Plot 2 and Sub-plots 2 and 3 of 17 patients. The two extracts below indicate patients' accounts of the progression of their illness while they were receiving ineffective treatment. This theme was also related to the

misinterpretation of either chest X-ray results or the patients' self-reported symptoms. The following quotations from two patients highlight this theme.

> "'I told my GP, I started to cough a lot with phlegm. He said, 'I should take cough syrups'. I also thought it may be due to weather changes. So I took the syrup for about one month. And then, I went back to the GP, I still wasn't feeling well it was getting worse and worse and they said, 'I should take antibiotic' Every time I go there, he said 'I should have another course of antibiotic...'" (pt.23 – Coercer Core Story – Plot).

> "when I first contacted my GP, he referred me for X-ray ... he said I had pneumonia prescribed me a course of antibiotic, then after one course, it did not work I had another course and not getting better he said, 'for some reason I'm not getting better', and he referred me for chest x-ray and blood test to be done. From there, they found out one of my lungs was severely damaged a lot of TB infection there TB did not come to GPs mind - he thought it is pneumonia", (pt.38 -Tolerant Core Story – Plot).

Theme 4: Kept on painkillers for long time: (cycle of unhelpful pain killers)

For most patients, the treatment offered by doctors often resulted from their illness being judged to be minor and not warranting undue worry. They were advised to take either pain relief or pain killers and, at times, to switch to stronger brands of medication. Similarly, this category revealed that neither the antibiotics nor the pain killers/relief given to the patients were effective, and the patients concerns about the medication were not taken into account during consultations. The quotations from the three patients below highlight this theme.

> "I remember one week I had to go to GP every day They said I had asthma and they gave me inhaler when I used inhaler I cannot wake up I could not walk I had to sleep I told my GP this is not my medicine at the end of March I started vomiting, I cannot speak loud I start coughing when I speak, vomiting cannot climb stairs cannot sleep at night. " (pt.12 - Doubter Core Story – Plot).

> "The GP in Walk-in Centre did not give me proper medication he only gave me one cough bottle its only common cough syrup. He said 'I should take cough syrup and if carry on taking it for one week I can make it'..." (pt.21 – Sufferer Core Story – Plot).

> "From May to December, I went to GP for long time...In December, the pain is getting worse. The GPs said they could not do anything, only give pain killers. ..." (pt.11 - Sufferer).

Category 2: Referral

Within the category of referral, the pre-diagnostic stage of the patients' experiences involved: an immediate referral for testing; a referral after failing to respond to treatment; a referral only when critically ill; or applying pressure for a referral.

Theme 1: Quick referral pathways: (uncertainty of illness)

The theme of 'quick referral pathways' in the pre-diagnostic phase featured in the narratives of eight patients who reported their immediate referral to diagnostic centres with or without treatment in *Plot 3 subplot1 of* stage 1 analysis. The plot and sub-plots containing this theme involved being referred to an orthopaedic, ENT, A&E and chest department. The

nature of quick referral pathways and the patients' experiences of pathways were related to the differences between the types of TB which the patients were experiencing. For two patients, direct referrals were made to chest clinics, and two patients were referred to A&E following acute pneumonia. However, the four patients that were referred to orthopaedic departments and ENT units had a non-pulmonary form of TB. This theme reveals the issue that health professionals made every effort to refer their patients with uncertain clinical illnesses. The appropriateness of their referral pathways determined the patients' experiences of follow-up care. The quote from *pt.19* below highlights this theme when the referral was made to right specialist care.

> *"When I went to see her GP after feeling cough the night before the GP sent me to chest clinic for X-ray test...she did not give me any medication ...she said she did not know what it was and she wanted to investigate..." (pt.19 - Accepter Core Story – Plot).*

In this quote, the patient in the accepters group is explaining how her referral was made directly to the chest clinic, without treatment. The quote also seemed to indicate that the GP who was uncertain about the patient's illness and wanted to investigate in response to the patient's 'cues'. As discussed in Stage 2 of the analysis.

Theme 2 Referral when antibiotics do not help: (after no response to treatment)

The theme of referral *'after no response to treatment'* was described by six patients who had been told that they would be referred if the antibiotics did not work. These patients described how their symptoms worsened despite taking antibiotics for many weeks and months. However, the lack of response to antibiotic seemed to necessitate a referral by the doctor, as the quote from *pt. 38* below illustrate.

> *"After the first course of antibiotics, I told my GP, 'I'm not getting better'. He then said, one course did not work, so I had another course. Then suddenly I started to feel worse. He said 'for some reason 'I'm not getting better' and he said I might have TB. He then admitted me as an emergency into the S33 General Hospital. From there they actually checked my sputum and the test itself confirmed TB." (pt.38 – Tolerant Core Story – Plot).*

Theme 3: Referral when critically ill: (Critical illness)

> *"...I went back to GP again I was in agony could not walk, running hot and cold. The lump was growing the size of tennis ball then they referred me..." (pt.11 - Sufferer).*

The theme of being 'referred when critically ill' was found in seven patients' stories of how they were only referred by their GPs when they became critically ill in Plot 3, Subplot 3. The quote from the patient above describes how she was in agony and that she could not cope with the pain, and that only then was she referred by her GP. In the extract below from pts: 21, 28 and 32 (sufferers) describe how they were in serious pain before they were referred by their doctors. The failure to investigate their illness properly led to three patients being referred to hospital units unrelated to their illnesses.

> *"My cough was increasing all this time.... and I went back and they said they cannot give me an appointment bcause they have given me a referral letter to S322 hospital diabetic.....and cannot treat me. I was feeling very angry then." (pt.21 – Sufferer Core Story – Plot).*

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"The GP thought it was just an infection. He gave me antibiotics......appointment for blood sample ...four weeks went...The tumour in my neck was growing ...I started to get fever at night...he then referred me to ENT ..." (pt.28 - Sufferer).

"It was in January. I had a couple of blood tests at the GP. It showed that it was negative .... For a couple of months after that, I started losing weight and losing my appetite. The GP then referred me to the orthopaedist doctor inS11 hospital....," (pt.32 - Sufferer).

Sub Theme 1: Being critically ill and taken into A&E: (self referral)

The theme of *'self-referral'* is a sub-theme of *'referral when critically ill'*, and was found in eight patients' stories (in plot 3 subplot 3) who spoke about how they were critically ill and needed to seek emergency care. Amongst these patients, three had already been referred by their GPs and were waiting to see a specialist, but reached a state of collapse and were then taken into A&E. Patient 12 described how she became seriously ill and could not breathe after her GP had referred her to an asthma specialist, and so she was taken into A&E.

"The GP took a blood thyroid tests and referred me to an asthma specialist. After the GP referred me to the asthma specialist I was staying at friend's house I was ill, and could not breathe my face changed its colour. I called an emergency ambulance and was taken to the STH A&E", (pt.12 – Doubter Core Story – Plot).

Theme 4: Applying pressure for referral: (pushing for referral)

The theme of 'pushing for referral' was found in the stories of six patients (presented in Plot 3, Subplot 3) and highlights their experiences of not being able to obtain referrals, receiving repetitive ineffective treatment and experiencing no hope of finding the cause of their illness. This led them to be critical of their doctors' actions and they demanded a referral. The need to 'apply pressure' suggests that the patients' experiences of their doctors' failure to take their needs into account resulted in the patients' 'pushing for referral', which involved challenging their doctors. This signifies the power of the doctor with regard to referrals and the patients' ways of dealing with a lack of referral. The extract below, taken from Part 23, describes how he was able to articulate his concerns that his illness would get worse if he was not referred by his GP.

"I told my GP I want him to refer me for an X-ray ... nothing else. I did not want any more antibiotics......then he said 'Wait two weeks, then you can go'. I said No, I have been waiting for two months. If I do not go now, it will go worse. Then he referred me for an X-ray. I went to local hospital and they did check me over and they admitted me straightaway."(pt.23 - Coercer Core Story – Plot).

6.2.2   Diagnostic medical help

Category 3:   Information

In the category of the patients' transition to diagnostic centres, the time and place of referral were particularly salient issues, according to the narratives. This is because some referrals did not necessarily lead to diagnostic tests. In this category, two main themes were found:

waiting too long after referral; and being referred to a department which was unrelated to the patient's illness (being misclassified).

Theme 1: Waiting too long after referral: (miscommunication after referral)

The theme of 'miscommunication after referral' was found in three patients' pathways to the diagnostic centres. The quotations below illustrate that these patients had to wait for a long time after they were referred for an appointment, and that they had to make enquiries about their referral. However, enquiring after a referral became a challenge for one of these patients, who described her unfavourable experience of talking to the A&E doctor. She described it as 'humiliation' in front of the other patients.

> "The GP said he referred me ... I did not receive anything. So, I went to the S11 hospital A&E. The doctor said, 'There is nothing in the X-ray and you are wasting my time'. ...so I cried but he treated me very badly." (pt.39 - Sufferer).

> "After referral I never received a letter, from S11 hospital. I called them up (S11) and they were able to trace back my details and they said, 'appoinment is definitely sent' ...I never received a letter. I think it might be due to postal strike." (pt.15 - Accepter Core Story – Plot).

> "The GP told me to have blood test do ultrasound as well. It took too long to get the appointment I was just waiting on pain killer for about two months....I went to S11 hospital they told me the appointment was next day I never receive a letter nothing. .I used to go to GP everyday as an emergency I was quiet ill ...suffering a lot ." (pt.21 - sufferer Core Story – Plot).

Subtheme 1: Not been informed: (inadequate information)

The sub-theme of 'inadequate information' was found in the extracts of four patients found in Plot 5 Subplot 1, who spoke about their experiences of a lack of information after the diagnosis of TB, or during the treatment follow-up process. The theme of 'inadequate information' which was found in these patients' stories indicate their experiences of not being informed about their illness, test results or treatment follow-up after being discharged from hospital. The quote from pt.11 and 30 are presented in order to highlight this theme.

> "When I was discharged, I was really out of it. They did not keep in touch with me. ...I was trying to phone but I was not getting the right department. I ran out of medication. I had to go to the GP.I did not know I had to come here (chest clinic) to get medication... They did not tell me. I do not remember them telling me...." (pt.11 - Sufferer) – Plot 5, Subplot one)

> "When I was in hospital I was very angry that I was not treated fairly by the nurses...I also had no explanation about TB meningitis ...the leaflet does not explain about TB meningitis. The information is not great...." (pt.30 - Tolerant).

The patients' experiences appear to suggest that the information provided fell short of meeting their needs at this crucial stage of their illness.

Theme 2:   Complicated pathways to TB diagnosis: (being misclassified)

The theme of *'being misclassified'* was found in the stories told by six patients *Plot 4 subplot 1* who described the complicated nature of their referral pathways and the length of time taken before they were able to reach the diagnostic centres. This theme was significant in two patients' experiences, as the quotations below indicate. These quotes were taken from the experience portrayals of *pt.21 and 12.*

> *"The WC GP referred me to diabetic clinic in the S22 hospital..."they could not do the test I needed to fast for the test'...So they gave me another appointment for a month. ...stayed at home and suffering ... the chest physician phoned me and said, 'I need to go to the chest clinic'. ...I told him 'they referred me to the S22 hospital and I did not know the reason'. He told me, 'not to take any of their treatments' and he then cancelled all my appointments with them. He told me 'I had TB' then he started my TB tretament," (pt.21 - Sufferer Core Story – Plot).*

> *"The GP referred me to S33 hospital in March this year They send me for asthma breathing test they wanted to measure my breathing I could not breathe anything. When I breathe out, I started coughing they said 'I couldn't do the test I should contact the GP to refer me to the specialist'. The GP then referred me to asthma specialist. They took blood, thyroid tests, everything", (pt.12 - Doubter Core Story – Plot).*

Being misclassified is a theme of miscommunication that describes the underlying feature of problem in doctor patient communication. *(Definition in Table 12)* From the story of the *pt.12*, one expression illustrating the connection between being misclassified and being misunderstood was "...*I was telling him I cannot breathe he was thinking I had asthma...*" As discussed in chapter 5, her medical help from her GP was not attending to her needs which led to her being misclassified.

Category 4:   Test

Within the category of test in the diagnostic phase, the patients described how they were given repeated blood, urine tests and chest X-rays by their doctors and were told that nothing had been found in the tests. The themes found in the extracts below highlight that difficulties surrounding access to TB test and difficulties surrounding test outcomes can be the reason why the treatment the patients needed was delayed.

Theme 1:   Advocacy; begging and fighting for test: (pushing for test)

The theme of 'pushing for tests' was found in three patients' stories of their experience of TB tests in Plot 4, Subplot4. This involved medical help in the A&E and chest departments of hospitals. The experience of the factors that led to them not being given the tests was related to a lack of a referral from a GP for one patient (numbered 17 in the quote below). The second is a referral by a GP that was misunderstood by a chest department doctor who

thought that the patient's symptoms were not related to TB and she needed to see gastrologist. For a third patient, it involved fighting for more tests after being told that nothing had been found in the tests that had already been performed. The relevant Subplot 4 also highlighted what these patients had done in order to obtain tests in diagnostic centres. The quote from Part 17 illustrates what the patient did in order to obtain the test.

> "...I went to St Mary's hospital ...They said, 'I should go to my GP and get referral for an X-ray' I told them, I donot have the doctor... then I went to the Citizen Advice Bureau and they sent me to the S31 hosp A&E ...they gave me an X-ray and they told me straightaway I got TB sent me to the chest clinic." (pt.17 - sufferer Core Story – Plot).

Theme 2: Uncertainty: assuming and doubting

The theme of *'uncertainty of diagnosis'* was found in the patients' experiences of diagnostic centres in Plot 4, Subplots 2, 3 and 5. The fact that tests failed to detect TB may signify the issue of confirming a TB diagnosis promptly for the patients. At times, the professionals put more of an emphasis on the test results, rather than the patients' stories of their illness, in their clinical decisions, as this quotation from patient 30 illustrates:

> "...the first time I was admitted... after three days, I was sent home without a diagnosis. I had similar symptoms... for another month... came back... then they kept me in for three weeks... I had a blood test, a chest X-ray and a CT scan. They... do not always come back assuming it is negative... I told the doctors I lost weight, that I was getting temperatures, headaches and vomiting blood' (pt.30 – Tolerant).

The lack of information from her test results seems to have led to the assumption that the test results would be negative. In this case, the underlying theme found in this patient's expression was the theme of miscommunication that characterises the patient's interpretation of the lack of any results against the background of uncertainty about her test results. The theme of uncertainty about test results was also characteristic of the quotation from patient 22, as his experiences of undergoing a long period of tests and a lack of communication about his test results appear to have reinforced his doubts about his diagnosis, as the extracts below indicate.

> "before CT scan, I had X-ray the in the middle of April a year ago. After one year, they told me I had TB Why? I think I cannot believe it ...the doctor said I had TB and the letter said I might. I had too many tests...CT scan and three to four times X-rays, blood tests, I don't know hundred hundred times blood tests" (pt.22 - Doubter).

The underlying theme found in this patient's narrative contained an expression with a clear description of doubt, which is, *'I cannot believe it'.* This was how the participant described the events that led him to not believe his diagnosis. These events, in part, seem to relate to the lack of information he received regarding several tests which he underwent over the course of the year. Doubting falls within the theme of *'denial'*, which was also prompted by the uncertainty and miscommunication of the test results and diagnosis, and being told after many tests that nothing had been found or being given no information. This same issue was also found in the story of another 'doubter', as the quotation below indicates:

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'...the GP referred me to ENT at S32 hospital and... the doctor in the neck and throat clinic said that it would take three months or more. They took blood and drained out some pus for the test... [but after the] first and the second tests, there was nothing...' (pt. 34 – Doubter).

6.2.3 Post-diagnostic (Treatment phase) medical help

Category 5:   Care and Support

Within the category of care and support, some of the patients described how after their diagnosis, they had different experiences of medical help while in hospital and in chest clinics. The following themes found in the extracts taken from the stories highlight this category of experience.

Theme 1:   Not taken being taken seriously: (unsympathetic care)

The theme of 'unsympathetic care' was found in Plot 5, Subplot 1 detailing the experiences of seven patients including those who were admitted to hospital and experienced a lack of support from the staff during their treatment and care who were insensitive at times and also unsympathetic. There was a common theme in the patients' experience of being told to stay in an isolation room and not being given the support they needed, which prompted the feeling of being ignored by the support staff and nurses on the ward.

"When I was in hospital I was very angry that I was not treated fairly by the nurses, I had to ask for my medications and I was not taken seriously... ...." (pt.30 - Tolerant).

"I was for one week on my own in a separate room ...I used to ask nurses to give me water for my tablets but they used to forget...I was not allowed to go outside. I used to wake up and pressed the buzzer ..." (pt.35 - Sufferer).

"When I was in isolation room, I could walk but they (staff) did not want me to walk outside my room.... So, I asked the carer, to collect the bin from my room. The carer told me that, 'I've got legs I should get up and throw them'. I just kept quiet and I did not do or say anything." (p36 - Tolerant).

These quotes, which address the theme of *'unsympathetic care'*, appear to have negatively affected these patients' experiences of their diagnosis. The participants' quotes described how professionals failed to understand their care needs or their need for information on their care procedures or to listen to their experiences of their illness. Lack of sympathy is a theme of miscommunication occurs when professionals failed to understand the needs for empathic care which leaves the patient feel 'being ignored' or 'not taken seriously' as was highlighted in the admission experiences of four patients found in Plot 4, subplot 5.

Category 6:   Treatment

The narratives suggest that, unlike the patients' pre-diagnostic, diagnostic hospital experiences, their experiences of the treatment phase, particularly in their pathways to chest

clinics, appear to be positive in a number of encounters. The following themes were found in the category of treatment in the patients' quotations below.

Theme 1: Feeling listened to and well supported (sympathetic care)

The theme of 'sympathetic care' revealed by patients' expressions such as 'well-listened to and supported' is found in the narratives of patients who were diagnosed and followed up their treatment in the chest clinic. The theme is also found within other themes under the category of treatment. The quote from patient 19 below highlights this same theme of sympathetic care feelings when the doctor understands the expressed concerns of the patient and responds accurately to resolve the needs of the patient. in chest clinic.

> "They are very good people and helpful people and I thank them for that. When I was experiencing reaction to the medication I told her (the consultant) she changed the tablets to stop allergic reaction." (pt.19 - Accepter Core Story – Plot 6).

The expressions 'I told her what I was experiencing', 'she changed my tablets' and 'I thank her/them for that' signify communication adequacy between the doctor and patient in that the patient felt her concerns were being attended to, and this created a positive experience for her. The two quotes below from patient 21 and 23 also demonstrate the communication between patients and staff in terms of an empathic staff-patient relationship: understanding; adequate information on the process of medical help; developing ongoing face-to-face interactions; patients' adherence with treatment; and patients' satisfaction are all key indicators of the construct. (see definition in Table 17 below).

> "The staff here (chest clinic) they are highly qualified you know. They treat me well and told me quickly what my problem was. They are helpful they write down everything for me in sentences." (pt.23 – Core – Story – Plot 5).

> "The day I came to see the doctor I started my medication in that evening when I came back home then weekly they given me treatment and three months over. I am having the treatment and I found this is better and they are giving me encouragement as well." (pt.21- Core Story – Plot 5).

Theme 2:   Feeling better after treatment: (no side-effects)

The theme of 'feeling better after treatment and no side-effects' featured in the majority of the patients' narratives of starting TB treatment. For some patients, 'feeling better with treatment' did not involve the side-effects of TB treatments. In the quotes below, the patients describe these experiences of the positive effects of treatment without noticeable side-effects and complications. They had no problems with their medication, felt well and noticed an immediate effect on their TB symptoms. The quotes from three patients highlight the theme of starting to feel better after treatment.

> "Since I started taking the tablet, I did not have any problem till now. I did not have any reaction. ...I am gaining weight I gained 2 KGs and they changed my tablets I'm now taking two tablets for two months that's it it is treally good ...till now I don't know how I did not feel problem with the tablets ... it is a very good treatment."(pt.21 - Sufferer Core Story).

"I had to take eight tablets I don't take tablets all my life I never had to take tablets suddeiny taking lots of tablets and then I said there must be something less than that. The nurse has told me that I'll need to have that for two months and after that the tablet will decrease in numbers at the moment I'm taking three tablets. I've no side effect."   (pt.23 - Coercer).

"When I start taking medication, I was feeling dizzy, tired and vomiting after eating any food . . . After two months, I felt a lot better: no cough, no tiredness, no fever and no skin reaction a lot better now." (pt.12 – Doubter Core Story – Plot).

Theme 3:   Needing longer treatment: (Drug resistance TB)

The theme of 'needing further treatment' featured in three patients' encounters with treatment and that of one other patient, who was on treatment for two months but felt no benefits. The patient spoke about her worry that she might therefore need a longer period of treatment. This quote represents just one of the various experiences of TB treatment. The extract below describes the patient's experiences of complications during treatment in various ways and what happened to her before she noticed any improvement in her health.

"They tested all the TB medication. The first line medication did not work they had to swap this medication. .They gave me the different, so all medication did not work and the X-ray shows that my left lung was severely damaged … The medications started working …so I'm not infectious anymore that's why I'm not wearing the masks …after for about three months I was in the Isolation Room." (pt.38 - Tolerant Core Story – Plot)

Theme 4:   Going through hell: (Side effect of Treatment)

"I took the TB medication.it was hell …hell… hell, …cannot get out of bed and do something…I felt like should I stop taking it then I was told I donot have to break it (stop taking) .." (pt.33 - Sufferer).

The theme of 'going through hell' was found in patients' stories of their bad experiences of the side-effects of TB treatments. These patients stated that they were aware of the unpleasant effects of TB treatment and that they were also aware that they needed to report them to their doctors and should not attempt to cease treatment. The theme of 'going through hell' not only featured in some patients' experiences of the side-effects of treatment but was also mentioned by others discussing the same types of experience. In the extract above and in the quote below, two patients describe these experiences of the side-effects of treatment in terms of their attempt to cope in order to get better:

"I was taking one of the medications is called Pyrazinamide and that gave me lots of aches and pain ....I could not walk, I was shuffling. I actually got disability living mobility allowance because of that" (pt.38 - Tolerant Core Story – Plot).

Theme 5:   Family/friends support: (Treatment Challenges)

The theme of 'family/friends support' featured in the stories of ten patients in Plot 6, Subplot 3 who had bad experiences of the side-effects of treatment. Many of these patients' experiences of treatment involved the support of their family members and friends. The narratives suggest that all of the patients who were interviewed had complete commitment to their treatment. The extract below highlights the patient's physical and mental exhaustion

and her impaired ability to function in normal day-to-day activities, as the quote from Part 38 illustrates.

> "For the last about two years I've not been able to do any proper house work. Cleaning, which is not my routine work because, I stopped everything, so my husband having to do that. I also feel depressed for having and letting my husband do that. He himself is not a well man, he has Insulin dependent diabetic, so it is hard to see him do all that when he is not well himself." (pt.38 - Tolerant).

As the quote also reveals, she felt depressed and stressed by not being able to carry on as normal, feelings to some extent also triggered by her concerns about her sick husband who has to do everything, which demonstrates the challenges posed by side-effects and their burden on the family.

Category 7:   Feelings about medical care

The ending of the stories (coda), plots and subplots revealed the patients' current experiences and their reflections on the past leading to the present. Analysis of this section moved on to look for themes contained in the patients' feelings and the meaning of their experiences. This category presented key themes that contained meaning of the patients' experiences 'before', 'during' and 'after' diagnosis, during treatment and in the present. The patients' accounts of their current feelings revealed how their experiences of medical help had changed over time.

Theme 1:   Feeling happier, better and hopeful: (treatment success)

> "I'm being a lot better, I can bend, I can walk and am a lot happier about myself." (p11 - Sufferer)

The theme of 'happier feelings' about the success of treatment was prompted by the patients' own assessments of the changes they had experienced in the symptoms of their physical illness. For some, what they had thought would happen to them changed from thinking about 'dying' to a 'chance to live again'. These feelings were prompted by the positive news they received from their doctors on their way to recovery, as the extracts below indicate.

> "I'm so happy about what the doctorr did here (chest clinic). He decided to start my treatment. If he did decide based on the test results, I would have died really. All the test results were negative everything. I am happy very happy now." (pt.12 - Doubter Core Story – Core-Story Plot).

> "The NHS staffs are helpful and they support me all the time. As soon as they checked it here (chest clinic) they treated me well and helped me well. I'm alright now, I don't cough anymore, ...If I had to do it again, I would do it again, and there is no problems",(pt.23 – Coercer – Core-Story plot).

Theme 2:   Regret about failure to diagnose early on

Some patients reported their ongoing reflections on aspects of their previous medical care; how they had managed throughout, where they felt it had all gone wrong, recollections of

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events and their views on their experiences. The theme of 'regret about failure to diagnose the disease early' (lost opportunities to prevent traumatic experiences) featured in the narratives of six patients (Plot 7, Subplot 4), who felt that their illness could have been handled better in order to prevent complications in either TB treatment and/or the severity of the disease. The quote from pt. 38 illustrates the point.

> "... it took six or seven months ... on pneumonia medication ... before I started TB medications I think this is what causes my lung to damage... if we all suspected TB ...I would have been able to start treatment earlier and ...it would have been minor TB...the normal medication would have worked... " (pt.38 - Tolerant Core Story – Plot 7).

6.3 Results of Categorical Thematic Analysis

The analysis in this chapter looked into the six plots and thirty subplots that were derived from the experience portrayals, looking more closely at their content relating to medical encounters. Of particular concern were the specific issues contained in the narrators' textual data (*plots and subplots*) words, phrases, and metaphors that may help to identify themes related to specific medical encounters. The content of the six plots was classified according to the type of medical help they refer to in order to categorise them into the following groups: consultation; referral; tests; information, care support; treatment and feelings about medical help.

In addition, 18 themes were inducted from 30 subplots (see in Table 16). Analysing the content of plot and subplots detailing medical encounters (doctor-patient communication) revealed several themes related to doctor-patient communication models proposed by Morgan (2003); Kreps and O'Hair (1995), as Table 17 shows. The patient-centred and doctor-centred consultation models explain the properties of effective communication and miscommunication contained in relevant themes inducted from the data. Table 17 below summarises the key model concepts and constitutive definitions associated with the themes inducted in this chapter.

Table 16 below presents the distribution of categories of themes by groups of narrators. These categories of themes formed the basis for my interpretive scheme that was designed in order to answer the key research question.

Table 16

Distribution of categorical themes by groups of narrators

CATEGORY OF THEMES / Patients	sufferers										doubters				coercers						tolerant				Accepters							
	11	17	21	24	28	31	32	33	39	37	34	12	20	22	14	26	27	13	23	40	18	30	36	38	35	15	16	19	25	29	41	42
First medical encounters																																
Misinterpretation of symptom.																																
Ineffective treatment																																
Misdiagnosed																																
Transition to diagnosis																																
Quickly referred																																
When treatment not helping																																
When critically ill																																
After pushing for referral																																
Sought help from A&E																																
Diagnostic encounters																																
Waited long after referral																																
Had to fight for test																																
Had lots of tests no results																																
Diagnosed quickly after test																																
Being misclassified																																
Endured long period of testing																																
Missing information																																
Being ignored																																
Doubts about diagnosis																																
Inadequate care/support																																
Treatment encounters																																
Quickly began treatment																																
Needed longer treatment																																
Felt better no side effects																																
Felt better but had side-effects																																
Felt listened and cared for																																
Cared by family/friends																																

	sufferers	doubters	coercers	tolerant	Accepters
In Group Commonalities	First contact and medical-help from professionals	Diagnostic encounters	First contact medical help experiences	First contacts medical help experiences	Medical help from professionals, referral and diagnostic experiences
In Group Differences	Experiences of transition to diagnosis and TB treatments	Experience of transition to diagnosis	Treatment experiences	Diagnostic and treatment Experiences	Treatment experiences
Unique about the group	Treatment experiences and support from staff in chest clinics	Diagnostic and treatment encounters	Referral pathways & Chest clinic staff support	Memories about earlier medical encounters	Positive experiences of pathways to diagnosis and treatment and also medical help

Doctor- Patient Communication/Relationship also referred as medical encounter
It is a type of communication and relationship which largely occurs while seeking health care. A patient with underlying health problem tells the doctor the nature of his/her concerns which has led to him/her come to the doctor. A doctor by his/her professional expertise, expected to listen to the patient's full story and undertake as much information as possible to decide necessary course of action to address specific concerns presented to him by the patient, (Morgan 2003).

Models , constructs and themes	Categories and definitions of model *concepts and research themes*
Doctors' consultation styles (models)	There is no one specific definition to this, Its categories include: **Doctor-centred** (Paternalistic) based on doctor's values; **Patient-centred** (Mutuality) is based on shared values); **Default:** no one takes responsibility; **Consumerist** patient's values dictate over the doctor's opinion, **(Morgan 2003).**
1. Doctor-centred	Doctor-centred consultation usually based on the premise that the doctor knows best he is the expert and the patient needs to cooperate with the doctor's advice. This approach is characterized by a focus on medical knowledge, assumption, and categorization amongst likely causes drawing from the bio-medical aspects of the patients' symptoms and also asking 'closed questions' as a means to elicit the necessary medical information, **(Morgan, 2003; Kreps and O'Hair, 1995).**
1.1 Miscommunication:	The process of recollection about the communication failure that creates difficulties in the paths to obtaining accurate diagnosis and treatment for the patient in the process of seeking medical help. Properties of this construct are: misinterpretation, misclassification, ignoring, no informing; misunderstanding and assuming.
Themes Inducted	**Definitions from patients' expressions of medical help.**
1.1.1 Misunderstanding	A theme about being misunderstood during the process of medical encounter. The lack of any effort to check whether there is good understanding of key messages exchanged between the patient and the doctor. According Tzanne (2000) it is about a mismatch between the speaker's meaning and the hearer's understands of the speaker's meaning.
1.1.2 Misinterpretation	A theme of miscommunication characterized by the lack of an ability to interpret the patient clinical history using accurate clinical knowledge and skills.
1.1.3 Misclassification	A theme of miscommunication characterized by the categorization of the patient illness story (history) into the wrong clinical terms leading to decisions on actions that are in appropriate for the patient.
1.1.4 Misdiagnosis	A theme of miscommunication characterized by the wrong clinical terms being used to define patient's illness (disease).
1.1.5 Ignoring	A theme about the presence of a lack of feedback during doctor-patient communication that indicates the lack of mutual communication dynamic and often takes a form of one sided communication.
1.1.6 Misinforming	A theme that refers to the miscommunication of information used to describe the experience of not knowing what is happening and missing information.
1.1.7 Assuming	A theme referring to the form of miscommunication of information exchanged characterized by doctor's preconception about a story of an illness told by the patient. A theme also characterized by feeling or sense of 'assumed negativity' of TB test by a patient when there is no information on diagnostic test results from the doctors.
2. Patient-centred	Patient-centred consultation usually relates to a consultation when the doctor aims to understand patient's illness explanatory framework in terms of his/her subjective experiences and interpretation of illness. The approach is characterized by sufficient understanding of details of background concerning the causes and onset of illness symptoms in which a doctor secures deep underlying issues of the patient's and explains and encourages the patient in the course of action that is needed to tackle problem, **(Morgan, 2003; Kreps and O'Hair, 1995).**
2.1 Effective communication	A process of adequacy of communication between doctor and patient that creates feeling of well listened to and being understood by the patient and the process of medical help adequately met needs and well supported. The process of this construct is empathic doctor-patient relationship; and understanding of clinical problems of the patient; adequate information on the process of medical help; developing ongoing face-to-face interactions; patients' adherence with treatment; patients' satisfaction are key indicators of the construct, **(Adler, 2007).**
Themes Inducted 2.1.1 being understood Attending	Definitions from patients' expressions of medical help. A theme being understood refers to the communication of information used to describe the experience of communication and medical help addressing expressed needs
2.1.2 well explained Informing	A theme being informed about effective communication that describes the adequacy of information
2.1.2 well supported Supporting	A theme well supported refers to the ongoing medical help provided used to describe patient's satisfaction from effective communication and relationship.

The Table format and structure adapted from (Fawcet & Downs, 1992: p.210)

6.4   Summary of the Chapter

This chapter began by locating categorical themes from core stories presented in Chapter 4's experience portraits. In this chapter, the plots and subplots found in the core story portrayals, supplemented with plots and subplots from stage one, were used to induct key categories and themes of medical help in order to answer the third research question: what do patients say specifically about their experiences of professional help?

In Table 17, themes inducted from the data were linked to two doctor-patient communication models – 'doctor-centred' and 'patient-centred' models. In Table 16, the categories of themes and narrators were grouped according to five typologies. The table shows that there are similarities between the themes of sufferers, doubters, coercers, and tolerant patients' accounts of their first medical consultations. The transition to diagnosis (referral pathways) for some of the sufferers involved a long period of treatment and being critically ill with TB. Similarly, most of the tolerant patients were also referred after lengthy and ineffective treatments. All of the acceptor narrators and two narrators from the doubter group were referred quickly by their doctors. The referral pathways for all of the coercers involved pushing for a referral. During diagnosis, however, all of the doubters experienced similar delays during the diagnostic phase of their medical help. Most doubters reported experiencing no side-effects. During the treatment phase, however, three patients from the sufferers group and one from the tolerant group had the worst outcomes of their TB treatment. Levels of support from the chest clinic staff and family and friends appeared to be no different between the groups.

The choice to induct themes from the data (theorising from a case), rather than using thematic narrative analysis or other analytic methods, was based on the key premise of narrative enquiry, Riessman, (2008:p.74) as discussed in Section 3.3 and also to make the analysis process more transparent for readers' interpretations, evaluations, and judgments. In the thematic induction process, relevant themes from the literature were not discussed in order to demonstrate how the generation of themes has been achieved through the analysis of participants' experiences.

Chapter 7 will discuss in more detail the themes and findings presented in this chapter and the preceding two chapters by drawing on the literature in order to integrate the main research questions of this thesis.

Chapter Seven: A Discussion of Integrated Research Findings: Narrative Representation

7. Introduction

The study began with a pilot study using exploratory research in order to generate the following research questions: What do patients say about their experience of their pathway to TB diagnosis and treatment?; How do patients tell the stories of their experiences of their pathways to TB diagnosis?; and What do they say specifically say about their experiences of professional help?

The aim of this chapter is to draw together the main findings of previous chapters, particularly patients' accounts and the themes inducted from them that are discussed in chapters 5 and 6. These will be linked with the literature in order to represent the integrated research findings in relation to the three questions addressed in this thesis. The chapter will also integrate themes inducted and linked to doctor-centred and patient-centred model 'concepts' in order to refer to the abstract properties of the research phenomenon (Fawcet and Downs, 1992:p.19) – the 'medical help experiences of TB patients' in this study.

7.1 Integration of narrative representations

The preceding three chapters presented the results and data analysis of the research questions that this research sought to address.

Chapter 4 explored the first research question through a descriptive analysis, highlighting key plots and subplots from participants' narratives. The second research question was explored in chapter 5 through a holistic analysis of plot forms, assessing narrators' descriptions of their transition to diagnosis. The categorical-content narrative analysis in Chapter 6 explored and inducted key themes from Chapters 4 and 5 in order to address the third research question. Themes explored in Chapter 6 were linked to two theoretical models – the 'doctor-centred model' and 'patient-centred model' of care.

The present chapter will attempt to unpack each theme embedded in the first-order constructs that was linked to the second-order constructs (see Table 17). Drawing on the existing literature, this chapter considers how the themes induced from participants' accounts relate to the theoretical models (see Table 17 above) and also to current TB policy in London. The discussion will begin at the point of participants' first triggers for seeking medical help (their experiences of illness prior to seeking medical help) and their healthcare pathways in three stages: the first medical encounter; diagnostic encounters; and treatment encounters. At each stage, the participants'

experiences of medical help and various themes contained within the accounts of these experiences will be discussed.

7.2 Help-seeking Prior Healthcare Contact

This study reveals that with the exception of two patients (pts. 36 and 27), most had no awareness of the risk of TB in the community in which they live. One of the patients in the main study (pt. 27) and three patients (pts.3, 4 and 9) in the pilot study had had previous contact with cases of TB in London.

Seven of the interviewees had thought that their malaise was trivial or a minor illness and chose to try a range of remedies before seeking help from healthcare professionals. Of these participants, self-treatment was reported by six patients and they took painkillers, cough syrups and herbal medicines or home remedies for a month. One patient thought that stress was the cause.

In response to an illness that the participants did not know about, their actions were rational and can be considered to be reasonable. However, the length of time taken to seek help due to the low level of knowledge of the risk of TB seems to highlight the underlying theme found in the pilot interviewees' stories about the lack of public education on TB. This is an important issue, particularly for these population groups who are at the greatest risk of TB infection in London (DH 2004: p.19).

Researchers in London who explored the perceptions and experiences of African TB patients concluded that misinterpretation of early symptoms by patients contributed to their diagnosis being delayed for between three weeks and 40 weeks (Nnoham et al. 2006). The findings from this study show that patients' misinterpretation of their symptoms only accounted for a delay of up to six weeks (ranging from three to six weeks) before contacting a healthcare professional. Delaying contact with a healthcare professional was not related to any perceived stigma or *'financial, transport or other considerations'* (Rubel et al. 1992: p.633). Furthermore, the participants' narratives also provide insight into how their descriptions of their interpretations of their illness and their responses to being unwell are consistent with medical anthropological literature on the *'illness explanatory model'* Kleinman, 1988 – (in Green and Browne, 2005:p.138).

It could be argued that their lack of knowledge of TB and their misinterpretation of their illness cannot be these patients' fault, but that it is in fact related to the healthcare systems' failure to communicate the risk of TB in the community, (Marais 2007: p.23-7). The patients' illnesses were mostly gradual in terms of onset, but for some, the onset involved acute illness or symptoms and pain which were perceived by the interviewees as requiring hospital care (pts. 4, 7, 18 and 25).

7.3 Healthcare Seeking

The patients' accounts also highlight how their experiences of illness and their decision to seek medical help involved those who were close to them: their families and friends. Including the pilot interviewees, 12 patients sought medical help from the A&E and WCs, rather than from their GPs, (pts. 2, 4, 6 and 7 in the pilot study and pts. 17, 18, 13, 20, 21, 25, 33 and 35 in the main study). Among the reasons which the patients gave for not seeking medical help from their GPs, were: difficulty in registering with a GP (pts. 2, 17 and 18); difficulty in making an appointment with a GP (pts. 13 and 35); a lack of convenience and care from WCs (pts. 33, 21 and 20); choosing to visit A&E rather than a GP (pts. 6, 7 and 25) and choosing a private doctor (pts. 2 and 4).

Two patients thought that their GPs would be unhelpful based on the experiences of their friends (pts. 4 and 20). The study findings echo previous research findings on the misinterpretation of TB symptoms (Nnoaham et al. 2006; Metcalf et al. 2007). Furthermore, Paynter et al.'s (2004) study indicated that differences existed between TB patients' pathways to TB diagnosis involving their GPs and A&E. Although Paynter et al.'s (2004) study did not assess the differences in the patients' pathways, in this study, the participants' descriptions of pathways involved private healthcare and WCs. Of the 12 patients who sought help from sources other than their GP, only five described having difficulty in registering with a GP or obtaining an appointment. The decision on where to seek medical help for the remaining seven patients involved contacting A&E departments and WCs, and depended on the patients' assessment of their illness and their choice and preferences, rather than a lack of access. This study of the participants' pathways to TB diagnosis and treatment involved three stages of medical encounters: first contact with a healthcare professional; diagnostic encounters and treatment encounters.

7.3.1 First medical encounter

The theme of *'being misunderstood or misinterpreted'* was found in the accounts of most patients who contacted their GPs and involved doctors in WCs and A&Es (see Table 16 above). Many of the patients were unaware of their risk of contracting TB and may not have been able to express their concerns clearly. However, the accounts of two patients who were concerned about the risk of TB and were unable to voice their concerns during their consultations illustrate this point:

> *'I told my GP that I had lost weight and I was coughing too much and felt tired... He said, 'it is a problem with the weather'. I told him (the GP) 'I need an X-ray'. He said, 'I should go only when it's a problem'... My sister's husband said that he also felt tired when he had TB. He told me, 'I should go and have a TB test'. I had the same conditions (TB symptoms) I thought it might be TB, so I made an appointment and came here (the chest clinic)' (pt. 27 – Coercer).*

> *'When I entered the room, I was continuously coughing. The GP got scared. The moment she saw me she asked for the mask. She actually said to me 'it has to be swine flu'. I just said 'oh god!' I had to collect the prescription and collect Tamiflu and I took it for one week' (pt. 36 – Tolerant).*

Drawing on sociological studies and other literature on doctor-patient communication typologies, the features of the patients' experiences in this study may reflect two polar types of consultations: 'doctor-centred' and 'patient-centred' (Kreps and O'Hair, 1995: p.91; Morgan, 2003: p.55; Szasz and Hollender (1956) - cited in Garrity, 1981: p. 218) (see constitutive definitions in Table 17, p.140 above)

The two extracts above indicate a doctor-centred style of communication, in which the patient's concerns fail to become a part of the doctor's clinical judgement (skills/knowledge) (Morgan 2003: p.54-6). This failure to involve patients' concerns relates to a lack of appropriate responses from the doctors to patients' illness history. As a result, the patients' experiences of illness failed to guide their doctors' opinions. The excerpts above also indicate how the doctors' frames of references, such as 'it's a weather problem' and 'it has to be swine flu' limited the patients' ability to express their concerns to their doctors. As the quotations also reveal, the patients' brief responses to their doctors' opinions: 'I need an X-ray', from pt. 27 or 'oh god!' by pt. 37 either coerced or tolerated their doctors' medical opinions and assistance. Tyler et al. (2002) note the value of feedback, in this case from the doctors. Feedback is the doctors' response in the communication process, e.g. when attending to pt. 27's 'psychological cues' such as 'I lost weight, I cough a lot and I feel tired' and to pt. 36's 'non-verbal cues of continuous coughing'. As discussed in stage 2 of the analysis in the preceding chapter, by being attentive and inviting patients to elaborate more thoroughly, Del Piccolo et al. (2011:p.151), the listener (the doctor) can delve deeper into the issues contained in these cues.

As part of a broader analysis, other factors may provide an alternative explanation for miscommunication during medical encounters in this study. Adler and Rodman (2003) state that communication is context-specific and involves key factors: feedback (two-way); dynamic (ongoing) and relation to physical, cultural, social-psychological or temporal factors. In an analysis of the context of communication between doctors and patients, the influence of these factors should be acknowledged. The sociological doctor-patient model of explanation referred to as the 'doctor-patient communication role relationship' in clinical encounters by Morgan, (2003) presents a more adequate explanation of the communication context. (see Table 17) These models can explain influences over doctor-patient communication, including: the patient's characteristics and behaviour; the time available for consultation; the doctor's consultation style and skills; the structural context (administrative and institutional context) and the patient's own preferences with regard to clinical discourse.

In my view, any interpretation of the communication between doctors and patients should take account of their respective ideas, feelings and points of view within the context of the wider influences that are relevant. For example, the time devoted to clinical consultation by GPs, doctors' clinical workload and the role of GPs as gatekeepers, Morgan, 2003) are particularly important

factors, as most patients seek medical help from their GPs at the peak of pandemics, e.g. during the swine flu outbreak in London. This situation is likely to have had an impact on doctors' time for clinical consultations and may have hindered risk assessment/clinical judgement due to doctors' 'clinical emplotment', a factor mentioned earlier in this thesis, as a result of an illness that spread across the population of London. In view of all of these factors, any interpretation of the communication context is complex and related to several factors, which in turn are linked to patients' characteristics and clinicians' styles of communication, which may provide alternate explanations, (Morgan 2003: p.56/7; Kreps and O'Hair 1995: p.87-92). Future research could investigate the role of wider influences on doctors' consultation styles and doctor-patient medical encounters and may explain the miscommunication associated with medical help for TB.

However, Forsythe (2001) employed a participant-observer account of a three-year project designed to build a patient education system using a mutual doctor-patient language for migraine sufferers. This study found that, adequate time with a physician was not a fundamental issue and that most migraine sufferers already had a great deal of information about their condition and were not in search of biomedical information. However, during ethnographic interviews, the researchers observed that most questions were asked by the doctors rather than by the patients, but the doctors were unable to 'hear' some of the most fundamental concerns of the patients. The doctor-patient discourse involved doctors avoiding topics they did not want to discuss, (p.101-5).

The evidence from this review revealed similar experiences of patients with regard to the misinterpretation of their symptoms by primary care physicians (Metcalf et al. 2007; Squire et al. 2005; Sagbakken et al. 2010) and delaying diagnostic tests for TB. Several researchers have reported that 'patients' personal characteristics may affect communication within medical consultations, particularly clinicians' consultation style' (Kreps and O'Hair 1995: p.91). The findings in this study suggest that the medical encounters described in the narratives of twenty patients with different socio-demographic characteristics, such as age, sex and education indicate that they experienced difficulties associated with healthcare professionals' ability to understand patients' concerns during consultations. Arguably, the issues faced by the patients appear to suggest that the encounters between the patients and their doctors did not characterize the NICE Recommendation for 'patient-centred care' (2006:p.6). (see Table 17, p.140) The narratives suggest that the patients' accounts of their consultations with their doctors resemble a doctor-centered style, which resulted in the misinterpretation of TB symptoms, and these signs being linked to: swine flu; asthma; pneumonia; changes in the weather; cancer and diabetes. The narratives contain communication contexts which, from the patients' viewpoints, contributed to their diagnosis being delayed and the patients suffering. This issue warrants urgent attention.

The doctor-centered consultation model, as indicated by Morgan (2003), Kreps and O'Hair (1995) was found to have direct relevance to the following themes within the concept of

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miscommunication: misunderstanding; assuming; misdiagnosis; misclassification; ignoring and being inattentive. Areas of agreement between the doctor-centered consultation style and these themes of miscommunication included the presence of 'the doctor knows best and the patient need only cooperate' ideals. In some cases, the focus on biomedical definitions and the classification of illness in terms of disease may account for missed opportunities to explore the hidden needs of these patients. As a result, essential features of the themes of miscommunication are expressed in different forms in order to highlight the communication context experienced by these patients.

7.3.1.1 Repeated visits to doctors

Most patients spoke about being kept on ineffective symptomatic treatment, and having their referrals postponed when they were prescribed either antibiotics or pain killers for a considerable length of time. The narratives described the patients' experiences of telling their doctors about their worsening symptoms and the lack of benefits from the treatments they received.

Storla et al.'s (2008) systematic review found that the cycle of repeated visits at the same level of healthcare providers, the offer of unspecific antibiotic treatments and failure to be referred for specialized healthcare were all part of the delay in diagnosis and treatment. Their review highlighted problems in primary care services with limited facilities for diagnosis, and found a poor level of knowledge of TB in 11 cases. Furthermore, Metcalf et al.'s (2007) and Marais' (2007) studies in the UK showed that most patients had repeated contact with their GPs and received pain killers and antibiotics for a lengthy period of time.

The patients' descriptions of their treatment encounters are related to their doctors' misinterpretations of symptoms and also demonstrate the doctor-centered consultation style discussed in the preceding chapter. Some patients were able to elaborate on the type of medical help they had experienced *(tolerant, coercer, sufferer, doubter)*, while others described their experiences as smooth and had no recollection of miscommunication (accepters). On the one hand, the experience of repetitive ineffective treatment resulted in a change to some patients' attitudes towards their clinical care. They needed to increase the pressure by 'coercing' their doctors to refer them, 'doubting' their doctors' medical advice as a survival strategy and searching for help in their worsening situation. On the other hand, the treatment encounters for some in the 'sufferer' and 'tolerant' groups involved continued reliance on doctors' knowledge and trust in their decisions, while remaining in considerable pain as the illness progressed.

7.3.1.2 The transition to specialist care

The narratives of the participants in this study suggest that most patients' accounts of experiences of being referred for specialist care involve difficult encounters. The themes are: referral after no

response to treatment (sufferers and tolerant patients); referral after putting pressure on the professionals (coercers); referral after being critically ill (sufferers); and quick referral (accepters).

Patients in the accepters group described how their GPs' interpretation of their illness and their direct referral to chest physicians was one dimension of their doctors' appropriate use of frames of reference (reflection), (Servellen, 1997:p.165) when dealing with the symptoms reported by patients during medical encounters. However, while the interpretation of the patients' symptoms was inappropriate, their rapid referral also led to complications in the patients' pathways to diagnosis as a result of being misclassified, as the excerpts from the accounts of two doubters (pts. 22 and 34), who were referred to orthopaedic and ENT (Ear Nose and Throat) units, illustrate. The second feature of referral by doctors is contained in the subtheme *'referral after unhelpful antibiotics or pain killers'*, which was reported by the tolerant and sufferer groups. However, for some patients, their concerns about the lack of benefits from their treatments were not taken into account by their doctors. The narratives of these patients (coercers) therefore involved *'putting pressure'* on their doctors or *'pushing for referral'* in some cases, following periods of ineffective treatments. The sufferers who were *'referred when critically ill'* suggest that their referral by their GPs was prompted by the severity of their illness. However, the accounts of two doubters and sufferers who sought care at A&E when critically ill suggest that inappropriate referrals to the wrong specialists led to these patients waiting too long to see the right specialist.

Patients' experiences of referrals by their doctors appear to relate to the sociological literature on GPs' referral behaviours. In their study of 303 mental health patients, Ridsdale et al. (2007) found that referrals from GPs were not necessarily related to the clinical severity of symptoms, but were instead linked to higher consultations, frequency of contacts by the patient and the patients' anxiety and concerns about their symptoms. However, in a separate branch of mental health studies involving GPs, Morgan et al. (2007) gathered GPs' accounts of factors determining their referral decisions. According to this study, the major influences on GPs' referral behaviours are: *'psychological'* – tolerance of uncertainty; *'attitudes'* – therapeutic value of referral and right to second opinion; *'clinical'* – GPs' confidence; *'patient factor'* – anxiety and pressure; *'patient-doctor interaction'* – communication; relationship, frequency and time, (p.31-4).

In this study, the patients' narratives were more akin to Morgan et al.'s (2007) findings with regard to GPs' referral behaviours than Ridsdale et al.'s findings, which only partially relate to the accounts of the patients in this study. Morgan et al.'s findings with regard to GPs' referral behaviours are relevant and include a counterpart to the four types of referral pathways described by participants as being consistent with their experiences. Areas of agreement between Morgan et al.'s findings and the themes derived from patients' experiential accounts included the 'psychological influence' – a tolerance of uncertainty which is consistent with the patients who described experiencing *'quick referrals'* to specialist care. The influence of *'attitude'* – the

therapeutic value of referral and patients' rights to a second opinion seemed to be consistent with the accounts of those patients who said that they were 'referred when critically ill'. The influence of 'the GP's clinical confidence' (I understand this to span from being less confident to being more confident) is consistent with a number of patients' experiences of referral after cycles of ineffective treatments. The influence of the *patient factor*, which includes anxiety and pressure, are consistent with some patients' need to *pushing for referral*. However, the influence of the 'patient-doctor interaction', and the relationship, frequency and time of this communication did not feature in these narratives. For example, in relation to the frequency and time of consultations, some patients were unable to obtain a referral despite having six to 12 months of contact with their GPs (pts.1, 38 and 39).

The accounts of two narrators also highlighted what they understood from their experiences of their GPs' lack of action with regard to their need for referral. A male 'coercer' stated that '*unless you put pressure [on GPs], they would not let you go through the system*' (pt. 23). This seems to relate to the 'role of GPs as gatekeepers' in reducing excessive demands on expensive acute care services (Morgan 2003). Similarly, a woman 'sufferer' also said that: '*His [her GP's] concern was his money, not my health – when GPs refer [a patient] for an X-ray they lose money*' (pt. 39). The meanings found in these patients' accounts suggest financial reasons for their experiences of delays in their referral by their GPs. Although, in Morgan et al.'s (2007) study, most GPs talked about the patients' '*right to referral*', it is not clear to what extent the gatekeeper role of GPs and cost considerations influence GPs' referral behaviours. Future research could further investigate this issue in order to assess the role which these factors play in GPs' referral behaviour.

7.3.2 The diagnostic encounter

There were a number of patient accounts which included the theme of '*waiting too long after referral*' due to a lack of communication about referral procedures and follow-up care for patients. Four patients (pts. 27, 39, 15 and 32) who were referred by their GPs to specialist services waited for a long time to see a specialist. One of the patients (pt. 32), who was unable to wait any longer due to the pain and having no hope of treatment, decided to travel abroad in order to obtain faster care in her home country of Tanzania (Africa).

Researchers have developed a framework for examining patients' experiences of the NHS care pathway. They have been able to categorise patients' experiences according to nine valued domains called the Picker criteria: "fast access; effective treatment; involvement in decisions; clear information about journeys; attention to physical and emotional needs; empathy and respect; involvement of family and carers; smooth transition; and continuity and coordination of care" (Coulter et al. 2005; Coulter et al. 2006 – cited in Gullick & Shimadry, 2008). The narratives contain

a number of issues in relation to pathways to specialist care which fall into the nine domains outlined above. The referral process may involve communication between three agents: *the patient* (receiver of care); *the referrer* (an agent of the patient) and *the receiver* (an agent of care). A number of explanations can be given that may account for patients' concerns about miscommunication after referral. Using the nine domains of the Picker criteria above, the referrers (GPs) and the receivers (consultants/specialists) are expected to create a positive experience throughout the referral journey through providing clear and comprehensible information about the place and time at which the patient is required in referral letters. A number of these patients' accounts suggest that the lack of information about referral appointments, including a lack of information about appointments, a lack of empathy, a lack of continuity and coordination of care while waiting and being treated badly signify problems in the communication between the referrers and consultants and these patients.

Paynter et al.'s study found longer delays for patients after being seen by GPs. Delays in attainting an appointment for a chest X-ray (nine days) and also appointments to see a specialist at the chest clinic accounted for a total delay of 14 days (2004: p.184). The findings in this research suggest that this delay did not involve waiting for appointment at chest clinics, but that instead patients were referred to other hospital departments by their GPs for non-TB related tests, which accounted for an average delay of two months.

7.3.2.1 Experiences of the pathways to TB testing

Complicated pathways to diagnosis and the theme of '*being misclassified*' featured in the narratives of six interviewees, (pts: 12, 21, 22, 28, 32 and 34). The patients' referral pathways to departments that were unrelated to their medical problems illustrate the theme of '*being misclassified*'. The implication that complicated pathways led to increased disease severity were highlighted in the narratives of three doubters and three sufferers.

The pathway of pt. 12, who was classified as an asthmatic, involved attending a community asthma team, meeting with an asthma specialist at Kings College hospital and undergoing several tests with no positive findings. Pt. 21 was referred to royal London hospital (RLH) s a diabetic case, underwent tests and appointments and, after referral, was unable to obtain any treatment from a WC. He described his experience as waiting and suffering at home. Pt. 28 was referred to the ENT at Newham General University Teaching Hospital (NGUTH) and was then transferred to Whips Cross ENT and admitted for four days for numerous tests and treatments. Pt. 22 was referred to the orthopaedic department at Guy's hospital and underwent tests for about a year with no clear findings regarding his back pain (which was associated with spinal TB). Pt. 32 was referred to the orthopaedic department at Middlesex hospital (MSUH and waited for two months with no treatment for the pain. Pt. 34 was told by his GP that he may have TB, and he was then referred to the ENT

department at Guy's, undergoing several tests over a period of three months. While waiting for the results, he was unable to obtain medical help from A&E on two occasions.

A review undertaken by the Health Care Commission (HCC), looking at care pathways for NHS patients, found that: "direct referral from a GP to hospital specialist is beneficial in reducing the number of visits a patient makes during the pathway" (Smith and Ross 2004: p.50). Furthermore, "a single referral route is more equitable for patients and they are more likely to receive consistent information leading to more equitable patient outcomes" (Sharp et al. 2003 - cited in Smith and Ross 2004: p.50). Given that pathways to TB diagnosis and treatment constitute the core emphasis in this study, the NICE clinical algorithms provide clinical prediction rules with high predictive values for whether clinicians will suspect the presence of TB (NCCCC-RCP, 2006:p.33). The TB commissioning toolkit also states that: "all TB patients should have access to secondary care diagnostic and treatment teams within two weeks and, where there is strong clinical suspicion on the part of the GP of active infectious TB, most services will aim to assess the patient within two days stating TB as a rapid access service" (DH 2007a: p.12). The findings from this study suggest that the patients' experiences of being referred to hospital departments where their symptoms do not necessarily suggest that there is a problem are perhaps a cause for concern in this study.

Metcalf et al. (2007) have noted the potential for a suboptimal diagnostic process when the core values of general practice are not applied. The values which they have highlighted are: 'continuity of care; considering contexts appropriately; and eliciting and responding to patients' ideas, concerns and expectations' (p.123). These values are at the core of the NICE guidance for 'patient-centred care' in relation to access: ensuring that patients receive appropriate and timely care according to established guidelines for referral; streamlining the pathway to diagnosis and treatment (through direct referral from a GP to a hospital specialist for confirmation of the diagnosis); and ensuring continuity of care (NCCCC/RCP, 2006: p.45).

My belief is that, in patient-centred care, the information which patients receive regarding their care pathways is central to their participation in their care. In my analysis of the narratives in this study, it became apparent that the accounts of six patients showed misclassification and complicated pathways as a form of miscommunication in their medical encounters. As Nahon-Serfaty et al. (2009) argue regarding this highly complex patient-doctor interaction matrix, mutual engagement in communication during medical encounters may lead to a more satisfactory outcome of the consultation and may improve engagement with health services (p.48-74). The doctor-patient communication (medical encounter) experienced by these patients signifies a lack of mutual engagement and a doctor-centred form of consultation that may explain the delays in the patients' pathways.

Difficulties in accessing tests for TB featured in the narratives of three patients. 'Fighting for testing' is the theme which refers to the challenges of access to the TB test: pt. 13 spoke about how

her husband needed to *'fight for the test'* in order to find out the cause of his wife's illness. Narrative metaphors, according to Lakoff, (1993) "rather than being a rare form of creative language, are ubiquitous, highly structured, and relevant to cognition" (cited in Zachary et al. 2004: p.1). While fighting usually has connotations of war and is viewed as an unpleasant activity, the "medicine is war, this metaphor perhaps encourages the virtues required to survive the long hours and intense hierarchies of hospital life" (Hodgkin, 1985: p.1820). In this case, the metaphors of *'fighting for testing'*, *'begging for testing'* and also seeking *'advocacy support'* represent the patients' personal experiences of feelings about unmet expectations regarding their healthcare providers. In the case of pt. 17, a lack of access to the TB test meant that the patient needed advocacy support from the Citizens Advice Bureau (CAB). Pt. 39 also described her experience as *'begging for testing'*, and a repetition of her previous experiences of *'not being listened to'* by doctors in A&E and another hospital department that could not provide the test she needed. The narratives from these patients' accounts reveal that subsequent tests for all three patients led to their diagnosis with TB (for pt. 13, it was a CT scan result, for pt. 17, a chest X-ray result and for pt. 39, the results of sputum tests).

7.3.2.2 Experiences of TB tests

Most researchers have acknowledged that patients' need for information is greater at particular points in their illness and suffering. The narratives suggest that the theme of uncertainty about the diagnosis was apparent in the patients' diagnostic encounters. The narratives from patients: 12, 13, 20, 22, 26, 24 and 34 suggest that they endured lengthy diagnostic tests. These patients spoke about having a great deal of contact with professionals. They not only found the diagnosis process to be lengthy, but also confusing. The narratives suggest that while the doctors' medical opinions about the patients' symptoms were suggestive of TB, the sputum laboratory test results for three pulmonary TB patients did not confirm the presence of TB. The accounts of four non-pulmonary cases suggest that their X-ray and CT scan results were also non-suggestive of TB.

The experiences of two patients (pts.12 and 26) highlighted that, while their chest X-rays revealed abnormalities, further confirmatory sputum tests were unable to provide a definitive diagnosis. Both patients were told by the A&E doctors that their illness was likely to be related to TB, rather than other illnesses. While pt. 26 tested positive after a bronchoscope examination, the tests failed to detect TB for the remaining six patients.

The findings in this research are similar to Sagbakken et al.'s (2010) findings, that most patients in Norway who experience a lengthy diagnostic process have non-pulmonary rather than pulmonary TB. The tests had failed to either detect TB or suggest TB-related abnormalities from sputum smears, pleural fluid samples, CT scans, ultrasound scans or X-rays. The NICE guidelines state that: "if possible, a posterior-anterior chest X-ray suggestive of TB should be followed by at least three sputum samples with one early morning sample for microscopy and culture before

starting TB treatment... or, failing that, within seven days of starting treatment". It also states that: 'if there are clinical signs consistent with diagnosis of TB, and treatment should be started without waiting for the culture results.' Furthermore, the guidance also states that: "once a diagnosis of active TB is made, the clinician should refer to a chest physician with training and experience in TB who can initiate treatment." (NCCCC/RCP, 2006: p.45).

Evidence from diagnostic accuracy of tests[12] varied. The diagnostic accuracy of tests is measured in terms of test sensitivity and specificity. The sensitivity of the test is related to its ability to detect TB and abnormalities which suggest TB accurately. In terms of accuracy, the higher the sensitivity of the test, the lower the false negativity of the test. The specificity of the test relates to its ability to accurately prove that the disease is 'non-TB', if the patient's illness is 'truly non-TB'. As the specificity of the test increases, the false positivity decreases. In addition to the limited effectiveness and accuracy of these tests, a number of other factors also determine the specificity and the sensitivity of test outcomes. For example, the severity of the patient's illness; the accuracy of the test administration and interpretations of the results and contamination of laboratory samples are known factors. All of these factors may have resulted in these patients' poor experiences associated with their test results.

Acknowledging that there is a lack of clarity and limitations to patients' accounts of the specific tests which were undertaken, the theme of 'uncertainty about diagnosis' was partially expressed in the form of failed tests, which also played a part in delaying the transition to diagnosis and treatment, especially in these patients' experiences. Future research could investigate this area in order to understand more fully the delays in treatment associated with the failure of TB-specific tests for patients.

7.3.2.3 Being diagnosed with TB

The narratives suggest that, compared to the pre-diagnostic and diagnostic phases, during which the majority of patients were uncertain about the causes of their illness, for most patients, the discovery of their TB diagnosis was unexpected, and resulted in shock, confusion and disbelief (denial). Some patients even spoke about how they felt happy that they knew the cause of their illness, and that they believed in the success of TB treatment. For some patients, the diagnosis involved a period of reflection on what they had known and believed about TB and a reassessment of their experiences of undergoing tests over a considerable length of time. Their descriptions of the

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[12] In diagnostic accuracy tests, "chest radiography sensitivity was reported as being between 61% and 67%; acid fast bacilli sputum microscopy sensitivity was reported as being 70% or over; and CT and cerebral ultrasonography revealed TB abnormalities in 60% of cases (Polimino et al., 2007). The sensitivity of gastric lavage compared with culture was 39%, specificity was 99%, the positive predictive value was 88% and the negative predictive value was 90% (based on three gastric lavage samples). The sensitivity of histology (using a variety of specimens, most frequently lymph nodes) compared with culture in an East London population was 97%, with a positive predictive value of 69% for tuberculous lymphadenitis. The sensitivity, specificity and positive predictive values for cytology were 78.5%, 73% and 76.7% respectively. In a US study of lymph node specimens where the cytology report was compared with culture results, the sensitivity of cytology was calculated to be 72%" (NCCCC-RCP, 2006: p.40-46).

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events that led to their doubts about their diagnosis seem to highlight their experiences of negative test results and the lack of information they received on why the tests failed to identify TB in the first place, as revealed in the stories of pts 22 and 34. This underlying theme, found in these patients' expressions, was also exemplified in the story of pt. 30, who said that:

> 'They did lots of tests and they do not always come back to you. If they did not say anything, I assumed it was negative' (Plot 3, Subplot 3).

This patient's description of the events which led her to assume that the test results were negative implied that they occurred due to a lack of information provided by the professionals. The meaning underlying the patients' doubts about their TB diagnosis can be captured in the data itself. For example, the circumstances which led to decisions being made about TB diagnosis and treatment also appear to account for pts.12 and 20's doubts, as highlighted in their stories. The theme of *'denial of TB diagnosis'* was reported by previous researchers amongst patients who reported experiencing the stigma associated with TB from community members (Nnoaham et al. 2006). The patients in this study, however, spoke more about their experiences of undergoing numerous tests that failed to detect TB and their experiences of the miscommunication of test results as being the reason why they did not accept or doubted the late diagnosis. Denial, as a theme, is also an indication of a communication context that requires a patient-centred approach in order to understand what has led to this behaviour. It is usually *'and indication of discrepancy between present behaviour (doubting) and the truth about the experience'* (Hergenhahn, 1999: p.467-500; Hillsdon 2006 - cited in MacDowall, 2006:p.74-85).

In the literature, denial is described as "a mechanism to escape consciously or unconsciously from painful events or feelings" (Dorpat 1983– cited in Chandra et al. 2007). It arises "as a result of preconscious appraisal of danger or trauma and the experience of a subjectively painful or distressing affect" (Dorpat, 1983 – cited in Chandra et al. 2007). It is also described as "a protective function... [and] often temporary response to overwhelmingly stressful and disruptive situations" (Horowitz, 1983 - cited in Chandra et al. 2007). In clinical encounters, the patient's denial can be described "as a conscious or unconscious repudiation of part or all of the total available meanings of an event to allay fear, anxiety or other unpleasant effects" (Wiseman and Hackett 1961 – cited in Chandra et al. 2007).

Weisman and Hackett's (1961) description of denial seems to relate to the narratives of two patients. Pt. 22 did not feel that he possessed certain key characteristics of a person with TB. He says: *'a person with TB is skinny and coughs a lot'.* For pt. 34, his denial was based on the belief that, as he describes it, *'he does not smoke, nor drink, none of his family had TB, so he does not accept he has TB'.* However, pts: 12 and 20 doubted their TB diagnoses due to test failures. Both patients decided to start their TB treatment without test confirmation. Three of these patients had already been on treatment for some months, except pt. 20, who had been receiving treatment for

only two weeks prior to the interview. With regard to pt. 20's decision concerning treatment, the NICE guidance states that: "clinicians should still consider a diagnosis of non-respiratory TB if rapid diagnostic tests are negative, for example in pleural fluid, cerebrospinal fluid and urine" (NCCCC/RCP, 2006: p.49). This explains pt. 20's experience of starting treatment based on skin test results in the absence of confirmatory test results from samples of pleural fluid. The treatment decision for pt. 12 (smear-negative pulmonary TB case) was, however, based on clinical signs which were consistent with the diagnosis of TB and treatment started without test confirmation by her chest physician, as discussed above. There is, however, a similarity between the findings in this study and Nnoaham et al.'s (2006) findings, in that all four patients who doubted their diagnoses have continued with their TB treatment and have also cooperated with all further tests which they needed to undertake.

7.3.2.4 Information and care after diagnosis

Following their diagnosis, many patients resort to undertaking searches on the Internet, asking friends for advice and seeking the opinion of other professionals about the specific type of TB they are experiencing. The story of pt. 30 highlights the theme of a *'lack of information'* during her diagnosis procedure and after her diagnosis, as an in-patient. She was unable to obtain a clear explanation of how TB meningitis is caused, and she described many of the leaflets provided to her as not explaining TB meningitis. These inadequacies of information about TB typify an unmet need which was found in the stories told by a number of patients (pts. 23, 37, 30 and 15). On the whole, most of the patients were very satisfied with the information they had received from healthcare professionals during their diagnosis, particularly patients who were informed of their test results in chest clinics.

In their study on young cancer patients Silver et al. (2009) noted a lack of information before and following their diagnosis, a lack of written information from GPs and dentists, and that many of the patients obtained their information from Internet searches (p.22). These researchers found that a number of patients they interviewed specifically recalled a television advertising campaign about oral cancer, suggesting that public information programmes have a valuable role to play in raising awareness and therefore providing some impetus for patients to examine their symptoms further (p.27). As Nahon-Serafty et al. note:

> 'The media is a privileged source of information on health and medical issues for the public. The media and cultural industries are also sources of esthetical and social models having a close connection with health, wellness, and illness ... The multiplication of information sources and points of view can lead to more individual autonomy, since this can contribute to developing a critical perspective on health care institutions, medical practice, and the healthcare system' (2009:p.58–9).

Feelings of *'being ignored'* and *'not being taken seriously'* fell within the theme of *'unsympathetic care'*, which emerged from the stories of patients who had experienced inadequate care during their stay in hospital. Pts. 30 and 35 both eloquently described their experiences in the isolation unit, where the hospital nursing staff gave them inadequate attention during their daily TB treatment. For one other patient, her experience involved the impolite attitude of the staff regarding her nursing care (pt. 36). Furthermore, two patients, pts.12 and 38 also spoke about their experiences of not knowing what was going on and noticing strict infection control practices in a way that made them feel that their care was insensitive to their needs, as highlighted in their experience portrayals.

Pt. 38 described her experience of being *'covered up'* by a face mask and seeing everyone wearing masks and aprons and not knowing what was happening or how long she was staying for. Such a tense care environment, for pt. 12, was not only unpleasant, but she also felt that the environment exacerbated her illness. She was able to remove herself, as she was a smear-negative TB case. Amongst the pilot interviewees, a UK-born pulmonary TB patient (pt. 8) also described her experience of not knowing what was happening to her and feeling alienated and embarrassed. She described her treatment as like being in *'quarantine'*.

My representation of these medical encounters is from the perspectives of these patients. On a speculative level, such experiential accounts of the hospitals' isolation policies and the patients' recollections of care from the hospital staff, in my view, reveal an insensitive attitude to the patients' care needs. There was a failure to communicate information in order to prepare and explain to these patients about the infection control care procedures and what was happening to them. This seems to explain the lack of sympathetic supportive care and, to some extent, constitutes a form of *'institutional stigma'* associated with the isolation unit care practices. This particular issue was reported by patients in another study as 'stigma by healthcare staff associated with infection control practices' (Nnoaham et al. 2006). The findings in this study add to this theme as it is evident in the patients' repeated descriptions of being ignored regarding their medication, the withdrawal of personal care and their restricted movement while in isolation units, which was described as being alienating by a young student interviewee in the pilot study (pt. 8). Amongst the pulmonary TB patients, only two had smear-positive status (pts. 36 and 38). From their narrative accounts, it seems that the emphasis of the NHS on TB patient care underpinned by the NICE TB guidelines regarding 'patient-centred care' is not in accordance with these patients' experiences. Although their narratives appear to suggest a number of instances in which patients referred to their hospital experience as an unpleasant one, the experiences of insensitive care found as a result of isolation units' care policies are consistent with the accounts of these patients.

7.3.3 Treatment encounters

The theme of *'sympathetic care and support'* within the narratives suggests that the transition from the GP to the chest clinic brought a sense of relief for most patients. The plot of *'adjustment to TB treatment and follow-up care'* refers to the pathway to chest clinics, where a majority of the ambulatory TB patients started their TB treatment. Some of the TB patients who were admitted to hospital started their treatment in hospital and were then followed up in chest clinics.

The narratives depict a number of ways in which pathways to treatment were achieved. For some patients, this involved attending diagnostic tests in hospitals with the hospital chest physicians. These patients then received a follow-up appointment at the chest clinic in order to receive their results in routine weekly chest clinic sessions. The patients' experiences of medical encounters in chest clinics were an extension of their hospital care, particularly in two centres with community clinics. Here, I intend to refer to the context of their treatment encounters in reference to the patients' experiential accounts of adjusting to their treatment at the chest clinics. As discussed in Chapter 1, for most patients, medical encounters in chest clinics come at the final stage of their pathway to treatment. The narratives contain the patients' accounts of adjusting to their treatment, a theme which has many subthemes which will be discussed in this section

7.3.3.2 Treatment benefits (successes)

The theme of *'starting to feel better: effective treatment'* was found in the majority of patients' accounts of their experiences of TB treatment. The narrators spoke about their experiences of taking large quantities of different tablets. As they described it in their own words, these experiences were *'daunting'* and *'horrible'* and many stated that they did not like taking tablets. As Farmer (1997) notes, in doctor-patient communication in treatment encounters, the doctors' responses to treatment failure signify the deficiencies of Western cultural practices, by failing to meet the perspectives of patients as reasons for treatment failure and complications, (p.353).

The findings in this study, which are based on narratives, suggest that the chest clinic staff in all settings were instrumental in the patients' adherence to TB treatment, in contrast with previous research findings, (Munro et al. 2007). Narrative accounts indicate that each patient had a named specialist TB nurse who followed up their case, provided advice and facilitated the treatment process. A number of patients made references to how the TB nurses provided *'psychological and emotional support'* during their treatment encounters. Their narratives contained a number of doctor-patient and nurse-patient encounters in the chest clinics that involved sympathy, encouragement and offers of information for coping with the challenges of treatment. A female narrator eloquently described her relationship with the nurse: *'I call nurse M every day for any problems; she knows*

everything about how I feel and what is going to happen. I say to myself, 'if M said it, it is true' – she is a real psychological support for me' (pt. 27).

Garity's (1981) review of recent studies of clinician-patient interactions and treatment compliance was based on evidence from studies of *'contingency contracting (concrete discussions of specific behaviours and actions) between nurses and patients'* (p.217). He explained the importance of 'active patient orientation', 'social support' (which refers to material, intellectual and emotional resources) and 'explicit and precise communication' within the therapeutic environment, as these factors promote the patient's adherence to the treatment (p.217).

A systematic review of qualitative studies by Munro et al. (2007) revealed four major factors which interact in order to affect adherence to TB treatment. These factors are: structural factors (including poverty and gender discrimination); the social context; health service factors; and personal factors, (p.1234). These reviewers also categorised a number of themes from the 44 studies they reviewed in relation to compliance with treatment: "organisation of treatment and care; interpretations of illness and wellness; the financial burden of treatment; knowledge, attitudes and beliefs about treatment; law on immigration; personal characteristics and adherence behaviour; side effects; and family, community and household" (Munro et al. 2007: p.1234). Interestingly, a number of factors may be used to explain patients' experiences in this study which contributed to their adherence to TB treatment. In addition to the support from chest clinic staff, all of the patients reported receiving support from their friends and family as well. Most of all, their narratives described the quality of information provided by staff concerning why they needed to be conscientious about taking the correct drug in order to get better and to avoid drug resistance, which was mentioned by most of the patients.

7.3.3.3 TB treatment failures

Some patients spoke about their experiences of treatment failure, which formed part of the theme of *'longer treatment'* which was found in the narratives of four patients. Their narratives contained four invariant experiences which related to this subtheme and different patterns of treatment failure. The way in which the stories were told by each narrator appeared to suggest a causal link to experiences of delayed treatment as a result of GPs (pt. 38); as a result of the side-effects of treatment (pts. 32 and pt.37) and fear of treatment failure due to vomiting after taking drugs (pt. 39).

According to a literature review, mono-multi-drug resistant TB is defined as strains of Mycobacterium TB with in vitro resistance to isoniazid (INH) alone (mono-resistance) or alongside rifampicin (RIF) (multi-resistance), and both drugs are first-resort anti-TB drugs (Iseman, 1994: p. 2429; NCCCC/RCP, 2006: p.91). A great deal is also known about the theme of *'TB treatment failure'*, which has a number of causal factors: failure by the patient to take medication regularly; the physician's failure to prescribe appropriate drugs or the health system's failure to ensure that a drug is available or rarely problems associated with mal-absorption of the drug by the patient due to

dysfunction of the digestive system or substandard bio- availability of the preparation (Chan et al. 2002: p.1282). Furthermore, patients with a fully susceptible organism can become resistant (NCCC/RCP, 2006).

In this representation of the narrators' accounts, I will make particular reference to the accounts of the patients' experiences leading to their treatment failure. Two narrators' accounts (pts. 32 and 38) make references to the context of what led to their 'treatment failure': one started treatment in the UK and the other in Tanzania. On the one hand, the account of the UK-born woman stated that, in her opinion, it was hard to think of any wrongdoing on her part. According to the patient, she had taken all of her treatments in order to get better. In her opinion, the misdiagnosis and delayed TB treatment on the part of her GP had led to the advancement of her TB and her experience of treatment failure. On the other hand, the non-UK-born patient said that the treatment failure resulted from her experience of severe side-effects to treatment while in Tanzania, and she stated that there was the possibility that she had contracted a form of TB that was resistant to first-line treatment. Similarly, the non-UK-born patient spoke about side-effects and prolonged treatment (pt. 37). A non-UK-born woman also experienced no effects of the treatment and was told that she might have a form of TB which was resistant to first-line treatment (although this was not tested), which led to her fear of treatment failure (pt. 39).

One common feature that ran through these narrators' experiences was that they all experienced a considerable delay prior to their diagnosis. However, the causal factors emerging from the literature seem to explain the potential causes of the patients' experiences of treatment complications.

7.3.3.4   Side-effects of TB treatment

The stories about the side-effects of treatment often involved the patients' recollections of unpleasant experiences and memories of treatment encounters. The narratives suggest that the likelihood of experiencing side-effects was anticipated by all of the patients, because they had been informed of what to do when experiencing unpleasant bodily responses upon receiving the treatment. 'Going through hell' is a phrase that was commonly reiterated by those with severe side-effects from the drugs. Among the reported side-effects are: itching; fever; lots of aches and swollen legs; joint pain (being unable to walk or having difficulty sleeping due to cramps); feeling dizzy; vomiting after taking tablets; hearing problems; swollen eyes and blurred vision. As discussed in Chapter 1, almost all of these experiences are known side-effects of TB treatments.

For most of the patients who experienced side-effects, alternative TB treatments were subsequently provided and the drugs that were intolerable were changed. In some situations, however, the patients needed to continue when the treatments were seen as essential, e.g. pyrazinamide with steroids. For example, two patients reported unpleasant feelings of 'depression

and anger' after taking steroids that were offered to them in order to counter the hypersensitivity which came as a reaction to isoniazid, pyrazinamide and rifater (which usually contain INH, PZA and RIF) (pt. 36). Treatment with steroids is also routinely given in conjunction with TB treatment in the case of TB meningitis, (pt. 30) as it is clinically beneficial (Parry et al. 2004: p.333).

The side-effects of treatment affected some patients' ability to care for their dependants, and they therefore needed support from their husbands (pts. 30, 38, 13 and 24) and other family members (pts. 26, 26 and 27) and friends (pt. 29, 33 and 17). The theme of *'support from family and friends'* was participants' experience of coping with the side-effects of TB treatment and was common across those who reported side-effects. Some spoke highly about this support and considered it to be rock solid, helping them stay committed to adhering to the treatment. For one patient, support was provided by a friend, and, as the patient had no family in the UK, this led to his intention to continue his treatment in Sri Lanka where he had family support. In this study, the experience of TB treatment, and particularly the side-effects described by patients confirm what was found in the review undertaken by Munro et al. (2007), which I discussed earlier.

Following their TB diagnosis, all of the patients in this study were offered treatment within days, some even sooner. Their understanding of the need to comply with the TB treatment was so strong that almost all of these patients reported the success of their treatment and showed their commitment to its completion. Some patients reported having no problems with this process and were very happy with the explanation and information provided, as well as the care and treatment they received. Munro et al.'s (2007) systematic review of 44 qualitative studies that reported on the side-effects of treatment and adherence found a number of themes in relation to side-effects, including: may be real; anticipated; culturally interpreted; insufficient information; insufficient communication; and insufficient attention. The reviewers also collated the views of all primary researchers and the evidence to show that side-effects may also be overcome if the patient is sufficiently committed.

The point made by these authors about the importance of patients' commitment is consistent with most patients' reported side-effects of TB treatment. The NICE guideline emphasises that each patient is appropriately informed and involved in treatment decisions. If a patient refuses treatment, he/she is supported with regard to housing, social security benefits and social care services (NICE, 2006:p.9). The guideline also states that its contents may address important issues regarding how NHS clinicians interface with social care and voluntary sectors (NCCCC/RCP, 2006:p.7).

However, the narratives indicate that the support which was provided came mainly from family members and friends for almost all of the patients. The support from family and friends and the availability of sufficient information and follow-up care from staff contributed to the patients' strong commitment. Earlier in this thesis, I noted that this study focussed specifically on participants' experiential accounts of their medical help, and was not intended to provide an understanding of the

social care arrangements or help provided by other agencies. It was clear from the accounts of almost all of the patients that family support featured consistently in their reality, except in the case of pt. 29, who needed support but was unable to obtain it.

This is particularly important for patients with no family or friends to support them. Their ability to cope with the side-effects of treatment may affect their adherence to treatment. Craig et al. (2007b), in their study of social support following TB treatment, found a significant need of social care amongst the cohort of TB patients in London. They reported their observations of the difficulties encountered by nurses and clinical teams in ascertaining how to meet the various social care needs of patients, which suggests that there is a need for further training in the social model of care in order to mitigate complex environmental and psychosocial factors, (p.423). The findings in this study add to our knowledge of the value of such support for patients with small support networks and who are experiencing the side-effects of drugs

7.2.4 Reflections on delays in diagnosis and treatment

The narratives in this study contain some patients' recollections of the early stages of their medical encounters and the personal meaning of these experiences in relation to the severity of their disease and any complications which occurred. These stories demonstrate how past events can be reflected upon and can lead to the construction of meaning. As Becker points out, "...human experience is a valid, rich source of all knowing and the basis of human behaviour. The everyday world is a productive source of knowledge; we can learn more about ourselves and gain key insights into the essential nature of an event by analyzing how it occurs in our lives" (1992: p.11). This illustrates the way in which the narrators sought to reflect upon their experiences of the phenomenon in question and to construct meaning through their stories.

The narrative enquiry method created opportunities for the narrators to go 'back to the essence of their primary experiences' of the phenomenon and to mull over and interpret these accounts (Husserl 1962, 1977 - cited in Becker 1992: p.10). As Crotty points out, "if we lay aside, as best we can, the prevailing understanding of those phenomena and revisit our immediate experience of them, possibilities for new meaning emerge for us or we witness at least the authentication and enhancement of former meaning" (1998:p.78). This suggests, unlike researchers who have attempted to interpret/explain the severity of TB by linking it to patients' knowledge about disease aetiology and symptoms (Gibson et al. 2005), that this research, through the use of narrative enquiry, recognises that narrators construct meaning about the source of their illness and complications by linking it to their experiences of miscommunication and delays in obtaining treatment. Meaning is not created in their heads, but through storytelling and listening and the joint construction of meaning during the context of the interview. As was discussed in preceding

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chapters, social constructionist epistemology explains that the meaning of events is constructed by patients within specific time and place through interpretive dialogue and interaction with others (Riessman, 2008). From the accounts of some patients' stories, I found that each patient, in their own way, was able to sum up and explain eloquently how their previous experiences of illness and medical help had led to the severe complications or suffering they experienced. This is one of the main premises of this thesis, which seeks to understand the participants' accounts of their medical encounters through narrative enquiry and to understand reality from each patient's point of view.

7.2.5 Reflections on recovery and feelings about medical help

The stories all ended with the patients' feeling about the present and the future, with reassessments of their present state of health and their recovery process for the future, in relation to events they have previously experienced. Almost all of the stories contained positive feelings about the success of their TB treatments and, for some, remembrances of past events and recognition of the failure on the part of professionals to detect their illness early, causing the disease to advance and affect them in many ways. In this final stage of the patients' pathways, the participants' accounts of their medical encounters aroused feelings of happiness in almost every one. This involved a journey which ended in happiness for those who told me that they were cured of TB during their interviews and others in their follow-up sessions. Those who were happy felt fine and better. Their stories ended with reflections on the events that had led to their TB treatment, which had been crucial for the survival of their families. It was also unfortunate that some ended their stories by reflecting upon their traumatic experiences with TB and by recognising that their path to recovery may take time. However, these participants remained positive about the care and treatment they had received. Again, from the accounts of most of the patients' stories, it became clear that each in their own way was able to sum up how the final stage of their experience of medical help differed from the one before, through being listened to, having the situation explained and also being supported during their treatment encounters, and through recovery. This is one of the main findings of this thesis, which highlights participants' medical encounters with chest clinic staff during their diagnosis and follow-up treatment and which typifies the 'patient-centred care' which is in line with the NICE (2006) recommendations. I feel that it is worth flagging the issue of patients' encounters in the pre-diagnostic stage and, to some extent, the hospital setting in general because they typify 'doctor-centred' medical care. This seemed, in part, to contribute to the patients' accounts of their negative experiences in this study. In order to aid the integration of this chapter, in the following section, I will present a schematic description of the participants' experiences of medical assistance for TB (the phenomenon) for readers, (Lieblich et al. 1998). (see Fig 16 below)

Figure 16   The phenomenon of medical encounters for TB diagnosis and treatment
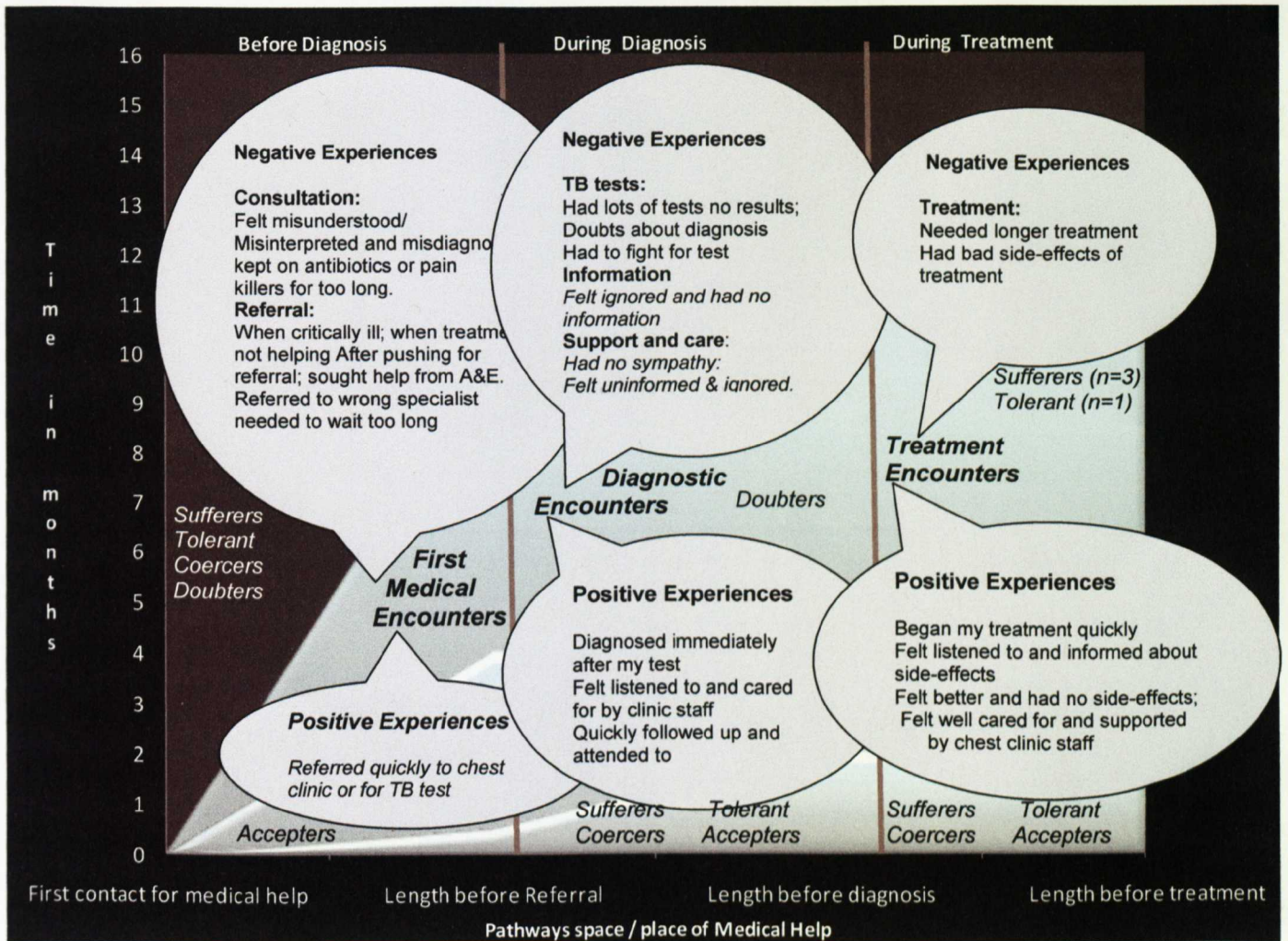
In Figure 16, a graphical representation of the phenomenon of medical help is presented. It seems necessary to explain the content of this diagram.

This diagram represents the three stages of the medical encounters in the patients' pathways. Time and space/place provide a visual representation of the length of time spent during the medical encounter and the key transitional stages in the pathways. Moving along the first section is the pre-diagnostic phase, referred to as 'first medical encounters', which represents the patient's experiences of their first contact with the healthcare system and key themes in medical encounters. The second process is referred to as 'diagnostic encounters' and contains key themes found in the narratives, which are diagnostic tests, information, care and support. The third section is the post-diagnostic phase, which represents the transition to the TB treatment phase; I used the

term 'treatment encounter' in the graph in order to relate it to the key themes. Similarly, the narrators' typologies are also indicated to relate them to the three stages of medical encounters.

The positive and the negative experiences of pathways to diagnosis and treatment through each phase are represented separately within the schematic circle diagram. Negative experiences (the barriers) are located in the upper quadrant of the pathway, adjacent to the lengthier timelines, in order to indicate their contribution to the delays associated with healthcare. In the lower quadrant of each circle is a schematic illustration of the positive experiences (enablers) of the patients' pathways to diagnosis and treatment, which are located adjacent to the shorter pathways to diagnosis and treatment.

7.4   Summary of the chapter: Medical help for TB (the phenomenon)

In this chapter, the discussion attempted to integrate key themes which were outlined from preceding chapters. These themes help to clarify the relationship between the concepts (doctor-patient communication) of the phenomenon of medical encounters and how they relate to the participants' experiential accounts. The patients' encounters involved interactions between themselves and their health providers (not only doctors, but also nurses and others), who operated within complex procedures and information processing systems. The phenomenon and its properties have been revealed through themes and concepts of models of communication. As Bates (1987) notes, a concept is a tool which facilitates the observation and understanding of a real phenomenon (cited in Fawcet and Downs 1992: p.19).

The chapter closes with a representation of key findings of Chapter 4 (in Table 10), from chapter 5 and 6 (in Table 16) using a graphical representation of medical help (the phenomenon) in Fig 16 above. First, it highlights that before diagnosis all of the 'sufferers', 'doubters', 'coercers', and 'tolerant' patients' accounts indicated similar delays. The typologies are located adjacent to lengthier timelines to indicate the negative experiences of their first medical consultations. Second, during diagnosis the accounts of all of the 'doubters' indicated the negative experiences of their diagnostic medical help as highlighted in Table 16 p.140. Third, the figure also highlights that three patients from the 'sufferers' group and one from the 'tolerant' group located in the top quadrant of the figure to indicate their negative experiences of longer TB treatment. However, the majority of narrators are located in the lower quadrant of the figure adjacent to shorter timelines in order to indicate the positive experiences of their medical-help during treatment.

Chapter 8 will present my reflections on the study processes: its strengths, challenges and limitations. It will also draw together the integrated thesis findings discussed in this chapter and summarize their implications for TB policy, future research and clinical practice.

Chapter Eight   Conclusions of the Thesis: Reflections, on Research Findings and Recommendations

8. Introduction

In this chapter, the narrative enquiry findings are drawn together to conclude the thesis. I reflect on research processes data gathering, challenges, limitations and review of key findings highlight what this study adds to filling in the knowledge gaps on the topic. A reflection on the processes driving the thesis questions (conceptual lens) and the analytical steps I have undertaken to answer them. The rationale and robustness of the study recommendations are discussed. The implications of emerged findings for TB policy, practice and future research are detailed and dissemination process and key target audiences are presented.

8.1   Reflections on the Study Processes

In this section I will reflect on my experiences from carrying out research with participants whose first language is not English, including those I needed to interview through interpreters. I will also reflect on how my choices of the analysis techniques are compared to other approaches in narrative research.

8.1.1   Reflection on Research Processes

I began this research with some anticipation of uncertainties, challenges and difficulties I may have encountered in obtaining access to research sites, recruiting volunteers, undertaking the narrative research in this most diverse population group, where English is a second language. Essentially, all these uncertainties necessitated the pilot prior to embarking on this main field research. My need for undertaking the pilot was recommended as an informative approach to testing the feasibility of narrative method in research and for modifying the research question.

Looking back, it was in the pilot when I considered the narrative approach as a suitable method in enabling pilot participants to "recall and reflect" upon memories of events they had experienced (quite readily). I also realized that the method created a relaxed environment for my participants as if they were having an ordinary conversation on the topic as opposed to a question and answer method. As I noted earlier in the thesis, the interviewee-centered story creation, rather than thinking about the clarity and ordering of research questions and participants' answers, provided me with access to listen to the chronology of events as they unfolded in their stories. I also learned quite early on in this process the importance of being reflective and deeply immersed in the

flow of interviewees' stories, crucial for capturing the chronology of events, time, places and people contained in the order of each story. In this way I have been able to picture their journeys from stories as they progress, regress or remain constant – the basic narrative prototypes (Gergen, 1988 – cited in Harvey, 2010:p.43). I thought my representation of narratives in holistic form, analyzing the pathways of participants' story lines graphically, may assist readers in evaluating the time dimension of events containing both positive and negative experiences. However, it is also appropriate to reflect on the challenges encountered in the research, particularly the participant recruitment and interviewing processes.

8.1.2   Challenges and Limitations of Narrative Interviews

The choice of my research settings seemed appropriate because of the severity of TB in the three settings. Most of all, I have been fortunate to receive support from staff throughout my field research particularly in the recruitment of volunteers. Although recruitment of volunteers for the pilot was targeted towards recent and longer-term migrants born in sub-Saharan Africa and South-Asia, I was only able to recruit one UK-born African TB patient. The focus on these ethnic populations has limited the participation of the homeless, individuals with alcohol and drug misuse or prisoners who would have been useful for this research. Selecting some patients from these groups in the pilot would have been feasible as they may not have needed professional translators.

However the lack of funding for this research was a major concern throughout the main field research, particularly in employing professional interpreters. The research necessitated looking into alternative sources of access to interpreters for five non-English speaking participants. As a result two types of professional interpreters were used: independent professional interpreters (interpreting services) and hospital advocates (professional interpreters – NHS employees). This is not without difficulty in ensuring quality of interpreting services provided by two different interpreters. Professional interpreters were referred by others as 'trained' or 'linguistic model' interpreters, (Turton 2003 - cited in Shaw, 2006). The two professional interpreters employed on a session basis by the Central Middlesex and St Thomas's hospitals chest clinics were subsequently involved in this research. As a result, information on their experiences and training could not be checked prior to interview.

The lack of funding limited my progress on recruiting further non-English speaking volunteers from September 2010 to February 2011. The recruitment of the remaining two Bengali and one Guajarati speaking volunteers occurred at the end my field work. For these volunteers, even though funding obtained from the LSHTM, through the Newham General University Hospital Trust (NGUHT) bilingual advocacy service all three patients were interviewed without the need to utilize the funds provided. The use of bilingual advocacy in hospital services has been historically

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associated with diversity of spoken languages in Newham and east London (Ansari et al. 2009: p.638). Bilingual advocates commonly take a dual role of literal translation (i.e. interpreting) and advocacy (cultural broker) role, giving people a voice (i.e. advocacy) (p.637). This dual role could compromise the purpose of this research which required literal translation of what is said - rather than 'advocacy'. I can reflect upon the challenge of using two different types of services in two ways.

On the one hand, the lack of planned arrangement for the two Somali - speaking interviewees interviewed through professional interpreters not only limited time to check the suitability of interpreters but also the accuracy of patients' transcripts could not be checked. On the other hand, although the bilingual advocates go through proper training and tests, due to their inherent role of advocacy and interpreting, this may lead to patients' accounts being altered (amended) rather than being literal interpretations. However, one of the participants, pt. 41 whom I interviewed through an advocate was able to feedback with support from his brother highlighting no changes to his data on his experience portrayal.

As noted earlier, all interpreters were informed about the importance of word-to-word interpretations as spoken by each interviewee. The four patients' voice data and transcripts could not be checked by other independent interpreters and ethical agreement for the option of employing an interpreter to validate transcripts was not provided. The section that follows will provide my reflections on data analytical models employed and their limitations.

8.1.3   Narrative Enquiry Analysis and Limitations

As noted earlier in the chapter, narrative enquiry has unique features in analysing meaning from stories of personal experience, particularly what is told and how it is told by tellers (Riessman, 1993). Narrative analysis is appropriate if it provides clarity 'to see how respondents in interviews impose order on the flow of experience to make sense of events and actions in their lives' (Riessman, 1993:p.2). As noted in chapter three, the narrative analysis techniques applied in this thesis are in line with Riessman's assertions: 'keeping stories intact for interpretive purposes', 'attending to context and content contained in long sequences of stories' and 'theorizing from a case rather than from components themes categories across cases' (Riessman 2008:p.74). (see p.63 above)

There is no canonical approach in interpretive work, but it is also recognized that each analytic model is related to certain types of research questions (Lieblich et al. 1998:p.14). There are techniques applied in narrative analysis, for example, an extended passage from an interview (Bury 2001:p.272), that can be described as thematic narrative analysis rather than the emplotment of core story plots and subplots applied in this thesis. I reasoned that opting for the thematic narrative

analysis alone would have not been suitable in answering my specific research questions and would not have given this study sufficient value. I would argue that such techniques would compromise the integrity of narrative contents because they do not provide the means to understand the contextual backgrounds and temporal sequences of experiences, narratives constructed by the narrators. The inductive aspect of narrative analysis not only suited the question posed, but also brought rigour to the analysis by making transparent the analysis process and the representation of participants' experiences (Riessman, 1993).

In addition, I was unable to use the previously tried and tested model of narrative analysis in relation to the analysis of participants' stories as it is noted that narrative analysis models take a structural, interactional, thematic and performative approach, (Riessman 2008). The emphasis of structural analysis shifts to the telling, the way a story is told. In chapter five the holistic analysis of plot form focus was on how story tellers make their story persuasive by selecting particular narrative forms. Arranging stories by plots and analysing plots for structure and forms meets the structural analysis approach. Furthermore, the categorical thematic analysis was achieved in chapter six; the induction of themes across cases interviewed has been linked with theories in order to meet the thematic approach in narrative analysis.

In interactional narrative analysis the emphasis is on dialogic processes where the 'interest shifts to storytelling as a process of co-construction, where story teller and listener create meaning collaboratively' (Riessman, 2008:p.31). The analysis employed in the thesis did not look into interactional (dialogic) processes; instead it focused on narrators' data omitting my prompts and nuances because the question posed did not require microanalysis of the language and interaction. However, I also realized that the core story experience portrayals used in the analysis did not highlight the co-construction of meaning of constructionist epistemology, and this is due to limited visibility of my presence in the portrayals. Furthermore, an incomplete, partial and selective approach applied in the representation of narratives (Riessman, 1993:p.11) in this thesis may also raise questions about the epistemological basis of this research. However, I began the analysis process through the 'tacking' and 'emplotment' of the narrators' data by revealing what is contained in the data, which meets the constructionist epistemology. Moreover, in Annex 3, p.247, I included the narrative interview Aide-Memoire applied in this research. I also included in Annex 4, p.251-4, one interviewee transcript highlighting my presence in the narrative construction to enable the reader to judge on the methodological and epistemological questions that may arise from the data.

The performative approach to narrative analysis is appropriate for studies of communication and detailed understanding of identity construction – how narrators want to be known, by using language and gesture, 'doing' rather than telling alone to express their identities (Riessman, 2004:p.5) and perspectives to their audiences. The holistic analysis of 'plot' forms undertaken in chapter five also looked into how narrators spoke about their stories of pathways to diagnosis. In so

doing, five typologies were inducted from the narrators' stories. As noted earlier in the thesis, analysing plot forms and types from narratives revealed how narrators wanted to be understood. In my view a detailed analysis of narrators' identity construction would not have served any additional value in answering the relevant thesis question. Having reflected in this section on the narrative interviewing processes and analytic models chosen, I would like to build on and reflect on the limitations I have discovered. In the next section I will summarize the limitations that I acknowledge are in this thesis.

1. A lack of direct access to patients in the recruitment of participants into the study limited to a search for volunteers who may have negative experiences of chest clinic services. As a result an absence of serious cases of treatment errors, highlighted by Mead (2006) and Branley (2009) may be a limitation on the findings.

2. Most participants in this study were ethnic minority patients. I acknowledge that the lack of meaning construction with no cultural frame of references in this thesis may present a limitation in my analysis of data. Furthermore, language skills to describe inner feelings and deep seated concerns on the part of most interviewees' accounts whose English is a second language may also be seen as a limitation. Moreover, interviewing non English Speaking (NES) interviewees through bilingual interpreters meant that the five patients' interpretive accounts may lack accuracy.

3. Difficulties posed by retrospective oral accounts for some patients interviewed at the end stage of their treatments, which meant their recollections were based on relatively distant events. The lack of core story feedback for fifteen participants due to lack of communication through postal mail and by phone. This meant the stories taken in this study are based on a single snapshot reflected at one particular context in time and place. Therefore it is not possible to see how these stories might have changed over time.

4. As the study is the first narrative enquiry of TB patients in the UK, this research could not draw on evidence from similar studies on the topic area. My findings are based on patients' accounts and this is the limitation of the method in that it does not seek to corroborate evidence from alternative data sources from chest clinic records or information from providers of their care. The narrators may have lacked sufficient understanding of the specific TB tests that they were given. As much as possible the patients' experiential accounts are a reflection of their experiences.

8.1.4   Reflection on Research Questions and Conceptual lens

My search into two areas of master narratives revealed multi-faceted determinant factors that are known to influence TB patients' pathways to diagnosis and treatment. In order to identify one overarching question and a specific method to be applied and tested on the topic area necessitated the pilot exploratory research. The pilot has been instrumental in driving the main thesis questions

and provided me with insights into 'narratives' as an object of study, particularly in events: time, context and content of pilot interviewees' illness experiences.

Although the pilot study moved the focus of this research into pathways to diagnosis and treatment, the question I asked of my research participants was designed more openly rather than tightly specifying the focus on their accounts of health systems and professional medical care, (Riessman, 1993: p.60; Green and Browne, 2005). This approach focused on triggers of medical help, time taken to seek help, pathways to diagnosis, participants' contacts with healthcare and covering their entire journeys to treatment. The benefits were reaped during the analysis. The question opened up topics when participants began to construct stories and respond to my prompts on the chronology of events they experienced (Mishler, 1986). The method chosen specifically for this study was tested and a thorough appraisal of how its appropriateness to the question posed has been provided. A brief overview can be described in two ways.

Firstly, the social constructionist lens underpinned by an epistemological thinking that recognizes social reality as a negotiated product of ongoing construction, interpretation and meaning-making - a reality produced by individuals continually testing those constructions in the light of new experiences (Schwandt, 2000). The approach adopted in this study recognizes that interpretive levels are partial and different interpretations are possible (Denzin, 1994; Riessman, 2008; Lieblich et al. 1998). In this research, research participants' interpretive accounts were highlighted in their portrayals and in Chapter 4 of descriptive data. My representations of their interpretive accounts were presented in Chapter 5, and Chapter 6 of the analysis and also in Chapter 7 of this thesis. The research method addresses these issues adequately to aid the reinterpretation of this report.

Secondly, the analytical steps undertaken in this study were particularly chosen to suit the questions I posed, and based on the three interpretive functions of narratives for analyzing experience. The interpretive functions relating to 'ideational' function were achieved by presenting narrators' description (interpretations) of their experiences in core stories and descriptive data 'first order constructs'. This approach is consistent with the research question and the method which is more concerned with case-centeredness and the participants' level of interpretation rather than a focus on themes and theoretical abstractions. In this I addressed the question of what patients say about their experiences of medical help in seven story 'plots' and thirty 'subplots'.

The interpersonal function was achieved by narrative holistic form analysis (analytic explanation). In this I looked into one particular 'plot' type that reveals the participants' form of telling about the transition to specialist care (diagnostic facilities). Analysis of narratives for 'plot' typologies was particularly valuable because it helped to look into the commonalities and differences for a group of patients. The approach is consistent with understanding how the narrators' perspective is understood from 'plot' types (Riessman, 1993; Lieblich et al. 1998). Looking at the plot types helped

me to see beyond the content of what they said the context between the behaviour/action displayed and the type of medical help experiences involving pathways to diagnosis in particular.

The textual function was achieved through categorical content (*thematic*) analysis. This type of analysis provided me with the opportunity to induct categories of medical help from narrative 'plots' and also themes from the 'subplots' that are clearly matched to first person's accounts. The empirical data from narratives analyzed thematically, linked to the doctor-patient communication models (*second order constructs*) in order to understand the narrators' experiences more specifically. In so doing, the study identified the complexity of medical help organization for TB patients and health service related barriers and enablers to the patients' pathways to diagnosis and treatment. As found in six pilot interviewees' experiences of health service related delay, miscommunication featured as the single-most serious factor linked to health service encounters which accounted for thirty patients being delayed for over a month (the cut-off point used to define delay by providers (Storla et al. 2008) before TB diagnosis.

The use of narrative enquiry in this current study is not only able to shed light on pathways to diagnosis and treatment but also provides accounts of events in time with sufficient contextual understandings of the phenomenon as experienced and reflected upon by the participants (Riessman, 2008). Experience is bound within the social world and it is through narrative that participants construct meaning of the unfolding events they experienced (Bruner, 1986; Polkinghorne, 1988).

From my (the researcher's) perspective, this study highlighted how our pre-conceptions influence how we view, understand, and interpret others. A social constructionist approach offers one unique way of understanding the experiences of others, which, rather than assuming reality as a fixed, observable, and measurable state, involves recognising the importance of patients' meaning construction, and attempting to understand the 'real' issues facing patients by paying attention to the content and context of their experiences. In the section that follows, the findings of this research are summarised as a way of concluding the thesis.

8.2 Conclusions: Review of Key findings

The study findings suggest that pathways to TB diagnosis and treatment are complex with a range of layers of health service related factors that are contributory to delaying diagnosis and treatment. The lack of knowledge about TB signs, symptoms and TB risk in London partially contributed to patients misjudging or ignoring symptoms and trying a range of home remedies. However, a greater cause of delay was miscommunication between patients and professionals which could certainly be improved.

In this study, patient-related factors contributed to delaying contact with health care for up to six weeks (ranging from three weeks to six weeks). This study also sheds light on new factors contributing to the decision making process regarding where to seek first medical help for TB (in particular, either from the A&E or the Walk-in Centres). These factors were: (1) lack of being registered with a GP. (2) Difficulty in obtaining GP appointment for emergency care. (3). Prior experiences of unhelpful medical encounter with GPs. (4).The inconvenience of arranging an appointment due to work commitments. (5). Judging their illness to be so serious that they needed hospital A&E care.

This study has highlighted the patients' accounts of their first medical help experiences from professionals. Including the pilot interviewees, the twenty three patients' accounts of first medical encounters in all these settings involved: (a) doctors' misinterpretation of patients' symptoms and not listening to patients' concerns; (b) patients' undergoing non-TB-specific routine tests that were unproductive. (c) The sixteen patients' accounts of repeated cycles of contacts with their doctors, being given pain relief and antibiotics that were unhelpful. The main finding of this study is that a large proportion (two thirds) of patients studied (n=30) experienced an unacceptable delay (greater than one month) and that this was largely the result of poor communication between patients and their doctors, coupled with low suspicion of TB despite the fact that the areas studied had known high levels of TB among at-risk groups.

The study also highlighted the extent of difficulties experienced by the patients in getting early referral from their GPs to the diagnostic facilities. Referral to specialist care for: (1) eight patients were quickly referred when their doctors suspected either TB or other serious illnesses e.g. cancer. (2). seven patients were referred only when they put pressure on their doctors to refer. (3). eleven patients were referred only when repeated treatments were unable to solve problems. (4). seven patients were referred only when they were critically ill. (5). five sought help from the A&E when they were critically ill. After referral to a specialist, three patients reported a delay in receiving an appointment from specialists and they needed to make enquiries directly to hospital departments. Sometimes misdiagnosis and misclassification of patients by their GPs and subsequent referral to the wrong specialists led to the complication of patients' pathways. In that, six patients had to wait longer to see specialists or to undergo more tests that were unproductive. This study has confirmed the findings of previous researchers on health service related delays (Paynter et al. 2004); miscommunication and misinterpretation of TB symptoms by GPs (Metcalf et al. 2007). This study has revealed the pre-diagnostic health service delay including six patients from the pilot for a total of twenty five (60%) of participants accounted for between three months and twelve months delay before their treatment.

The study has provided new insight into the challenges met by patients in undergoing the TB diagnosis process. Interviewees reported the experience of access to TB tests as difficult and found

that they needed either to fight for more tests to be done or had to seek advocacy or beg a doctor to test for TB in the first place. On the one hand, the most common experiences of patients involved delays which resulted from difficulties in obtaining TB tests, or the tests that were undertaken were unable to confirm TB for patients. The stories of patients (doubters), who had doubts about their TB diagnosis, highlight common experiences of undergoing numerous tests and not knowing why their test results were showing negative. In my view, this appears to have contributed to patients' doubts about the accuracy of TB test results. On the other hand, the TB diagnosis proceeded quickly following the results from chest X-rays showing abnormalities and subsequent lab confirmatory tests and other TB specific tests. This indicates how the TB testing processes may have contributed to the patients' experiences of medical help both positively and negatively.

The stories of some patients admitted to isolation units while undergoing TB tests also demonstrate the lack of attention given by staff leading to the feeling of being deprived of the care they needed. The narratives also suggest a lack of information on different types of TB. The information that was available did not sufficiently provide the answers they sought. Most of the patients researched on the internet. The diagnostic phase of medical help for these patients suggests the lack of adequate information from health care professionals given to patients at times of uncertainty and greatest need. The study has revealed miscommunication from health professionals to the patients about TB test results and reasons why the tests may not identify TB are likely to contribute to patients doubting subsequent diagnosis. Some patients were aware of the difficulties involved in making a decision to start their treatment. They narrated that their treatment decision was made based on typical TB symptoms and abnormalities found in either X-ray results or skin tests. The narrative accounts have to be interpreted with some caution because of limitations, as the narrators do acknowledge their lack of understanding of diagnostic processes and medical terminologies. However, this is part of the methodological limitations. The emphasis is on patients' experiential accounts rather than the accuracy of the tests that were undertaken. However, amongst studies in the UK, health service related delay associated with test failures is a new finding in this study. Narratives also suggest that for some patients, the chest physicians' decision on starting TB treatment was based on typical presentation of TB, skin tests and X-rays results. The study is unable to estimate the time between test failure and chest physicians' treatment decisions.

This study has also highlighted the extent of successes and challenges experienced by patients in making recovery from TB. For almost all patients, time from diagnosis to starting treatment was short, including patients who doubted their diagnosis. However, their doubt did not affect their acceptance of the treatment and attending treatment centres. The treatment phase brought several challenges for most patients who experienced side-effects from the TB treatment. Almost all said that they anticipated side-effects and were appropriately informed by chest clinic staff that continuing treatment would be essential for them to get better. The experiences of

professional support from chest physicians and nurses were described as *'being listened to well, friendly, sympathetic and informative'*.

Some participants reported they had no side-effects, only experiencing benefits from treatment. For other patients their experience involved both treatment side-effects and treatment benefits. For some patients, their treatment experiences involved no benefit. Some of these patients needed longer period of treatments for drug resistant TB. Most patients with side-effects of TB treatment also reported that they were coping with support from their family and friends. Continuing TB treatments at home was another challenge that not only affected some patients' ability to care for their children but also for themselves. Those participants reporting side-effects of treatments relied on family members and friends to care for them and their children. Almost all patients narrated that the information and follow up support offered from chest clinic staff was crucial for the success of their treatments.

8.2.1 How these findings support current public health efforts surrounding TB control

The research findings correspond to the most recent HPA annual TB report published in October, 2010. The report calls for scaled-up efforts to halt the continuing rise in TB transmission in the UK. It recommends action at different points in care pathways, particularly in urban areas with the highest TB rates; early diagnosis and prompt management of index cases; and for clinicians to have a high index of clinical suspicion in high risk groups especially among the non-UK-born population (HPA, 2010).

Given that pulmonary TB cases are infectious if undiagnosed and not treated early, the findings here are that almost all patients in this study sought medical help early (not delayers), but most were unable to obtain timely TB diagnostic tests in order to start their treatments which is lamentable. Health service related barriers in London are a risk to TB control efforts, particularly in cases of untreated open TB cases in London. The accounts of potentially infectious interviewees highlighted that some have been kept on treatment with ineffective antibiotics and painkillers by primary care physicians for several months despite complaining of typical TB symptoms. For most patients, including those with infectious forms of TB, events after referral leading to diagnosis and treatment were quick which may suggest the seriousness of their need for urgent care. The majority of patients' accounts suggest that there was little if any effort from providers in understanding their needs for urgent referral. As a result, some participants needed to either push for referral or seek care from their local A&E by themselves.

The health service delay associated with the primary-care physicians' misdiagnosis and misclassification of two patients resulted in severe advancement of TB and complications, loss of a lung, and cerebral spinal damage. These findings call for open discussions of patients' accounts

with all stakeholders in order to learn from these findings and lessen the risk of suffering for patients and prevent any risk of transmissions in London

8.3   Recommendations of the Study

The findings in this research have implications for policy, education and practice. The narrative method has cross-disciplinary relevance and the research approach is case-centred and non-disciplinary focused (Riessman, 2008: p.15). This was demonstrated in data generation and analysis of research. In my representation of TB patients' accounts, I have drawn from the work of scholars in sociology, psychology, anthropology, phenomenology, public health, medicine, and nursing. The findings have implications for policy implementation (management), education (research) and practice (clinical care) and so in the summary I would like to discuss these implications further.

8.3.1 Implications for TB policy implementation

This study was undertaken at a time when NHS managers, commissioners and policy-makers put particular emphasis on commissioners and providers listening to patients' experiences of health care delivery.

The narratives consistently point to providers' suboptimal communication as a primary factor resulting in delays of more than one month for two thirds of patients interviewed. The findings in this thesis strongly support the most recent HPA report recommendations for actions to prevent ongoing TB transmission in high risk areas in London.

By far the most common experience in patients' accounts illustrates the lack of awareness of TB risk in London. Given the recent rise in new cases, there is a need to increase efforts to improve public knowledge about TB, particularly in these sectors where TB is rated as the highest public health problem.

The DH NICE guidance on TB states that patient-centred care is the best approach to provide culturally sensitive TB care and tackle socio-cultural influences and wide misconceptions surrounding TB. The narratives suggest that there is a low suspicion of TB by primary care physicians, mostly GPs and also doctors in Walk-in centres that call for increasing primary care doctors' knowledge of the NICE core clinical guidelines and support to implement patient-centred consultation in practice.

These issues are related to the lack of information on referral processes involving timing of appointments for specialist care; the lack of adequate information on care procedures while patients were in isolation units; inadequacy of information contained in TB leaflets which do not adequately explain the various forms of TB; and the lack of information on results of tests undertaken for the

patients. The CMO TB report (DH, 2004) made a number of recommendations for providers of care in reference to these issues. Patient accounts appear to suggest that health professionals' current information shared with their patients does not reflect the report's recommendations.

Narratives suggest that the repeated cycle of ineffective treatments for many visits to the doctors led to severe advancement of illness and suffering for some patients. TB service commissioners and providers should listen to the voices of these patients in future service design and improve the pathway for TB patients.

Assessing treatment side effects and their impact on individuals and their networks is beyond the scope of this research. However my findings from this research also underline issues associated with side-effects of TB treatment and the burden on the family and individuals with no family networks. In two separate studies in London researchers found evidence of need for a social outreach model of care (Craig et al. 2007b) and developed a new model using TB link workers to mitigate factors that complicate TB treatment (Craig et al. 2008). The commissioners and providers may consider this new service model to improve patients' experiences of TB treatment.

8.3.2   Implications for future research

There is an evident need for more research which addresses the underlying factors hindering doctor-patient communication in TB service delivery in the UK. One way of enhancing knowledge of this concept in future research is by employing an ethnographic participant observation in medical encounters followed by face-to-face interviews with patients and doctors. The contextual factors surrounding patient-doctor communication are complex and context-specific and continue to be important to understand barriers that may affect communication during medical help for TB patients.

The evidence in this current study suggests misdiagnosis (misclassification of index TB cases) as contributory to the longest reported delay by up to twelve months amongst participants. Future research may investigate the contribution of inappropriate referral associated with diagnostic delay involving larger population groups.

The third area for future research concerns diagnostic delay associated with test failures. This study has methodological limitations to gather evidence on how delay associated with test failures occurred to patients with typical TB symptoms. As a further extension of this area, future research might also focus on how index TB cases are handled in the absence of confirmatory TB tests.

A fourth area for future research might seek to build on existing knowledge about GPs' referral behaviour in relation to TB. Research might examine whether financial considerations play any particular role in GPs' decision on antibiotics or symptomatic treatments rather than referring to

diagnostic facilities. A further extension might also focus on understanding how the GPs' awareness of TB in their area and their consultation style with patients influences clinical decisions.

8.3.3　　　　　　　　Implications for future practice

The patient's illness history is a key component of medical practitioners' and nurses' day-to-day practice with TB patients. The evidence from patients' accounts suggests that the medical encounter was unable to address patients' worries and their concerns due to suboptimal communication between the patients and their doctors. The NICE guideline on patient-centred care has implication for doctors to give sufficient time to listen to the patients' subjective accounts and to ask about patients' preferences and expectations. The findings of this study suggest that the patients' accounts of communication with chest clinic staff resemble the 'patient-centred care' at times of diagnosis and treatment follow up in chest clinics resulting in satisfactory outcomes for patients. My findings point to this one particular set of recommendations that of patient-centred care as essential to address the needs of TB patients, to gain their commitment and co-operations for 'regaining the upper hand on TB' (DH, 2004) in London.

Narratives suggest that the pre-diagnostic and to some extent the diagnostic doctor-patient discourse (medical encounter) is not based on mutualistic relationship 'patient-centred care'. As a result, the organization of medical help is unable to relate to the patients' illness story and worries. This seems to suggest an area of practice that warrants urgent attention by all clinicians working with TB patients to review their style of communication and identify current barriers to implement the NICE guidance on patient-centred care.

My findings on the patients' experiences of repeated offers of ineffective treatment by GPs, despite them voicing the lack of benefit from treatments they were given, question the clinical benefit and rationale behind some treatment decisions by GPs. The development of evidence-based guidelines for treatment decisions in diagnostic uncertainty for TB is an important issue which needs addressing to inform future decision-making by GPs and tackle referral delays. Recognizing the relevance of the thesis questions to the public health problem in London, I have stated my recommendations for key target audiences. However, the dissemination process will not exclude users of the service and my research participants. Following successful completion of the thesis assessment the dissemination of research findings will then be undertaken as follows:

1. A lay summary of key research findings - maximum three pages - organized for feedback to research participants and users via their clinicians and will be shared with community outreach workers working with TB patients and voluntary organisations.

2. An article will be written in style permitted for publication and will be presented for peer review following the LSHTM internal agreed guidelines for publication in public health policy journal.

3. Further dissemination of the research findings will include presentations to staff in Chest clinics, A&E relevant hospital departments, Walk-in centres, GPs and Health Protection Units (HPUs) in the three research sites.

4. A copy of the final thesis report will be made available to St Mary's NHS research ethics committee; to all R&D governance offices and the HPA in London.

5. Every effort will be made to present research findings for Academic paper(s) within the LSHTM and other universities in London.

8.4   Conclusion of the Thesis

In summary, through analysis of the data, the study has attempted to clarify and understand the experiences of forty-two patients' pathways to TB diagnosis and treatment in London. It has found the various types of barrier associated with doctor-patient communication during patients' medical encounters that contributed to delaying diagnosis and treatment. First, in this study thirty-four patients sought medical help promptly and eight patients delayed up to six weeks. Using the Storla et al. (2008) definition, patient-related delay is counted if a patient delays over two months before seeking medical help. The health service delay is constituted if a provider delays diagnosis for the patient for more than one month. The accounts of participants interviewed suggest that delay by patients is not a primary factor in their experiences of diagnostic delay. Their accounts also underline that they all had treatment almost immediately after their diagnosis. The pre-diagnostic care pathways highlighted by patients' descriptions of delay before referral accounted for thirty patients experiencing a delay in diagnosis of more than a month.

The narratives of these participants suggest miscommunication, particularly in how they described the various forms of medical help they experienced throughout the stages of diagnosis and treatment. The narratives also contained descriptions of events that led to their transition to diagnosis which involved: *suffering, tolerating, doubting, coercing* and only seven patients found the process smooth and non-problematic (*accepting*). Furthermore, looking at narratives by chronology of contacts and what they said by specific category of medical help reveals barriers and enablers of medical help experienced with professionals. These are answers to my questions in sufficient content and contextual detail to identify problems associated with delaying diagnosis and treatment. Given that the most recent TB report from the HPA highlights TB threats and calls for scaled up efforts, particularly in early diagnosis and prompt management of cases, it recommends clinicians' need for a high index of clinical suspicion (HPA, 2010). The findings in this research and the recommendations are particularly relevant to problems associated with increasing TB notification rates, particularly in Newham and Brent, as highlighted in this recent report.

My final closing comment is that the 'narrative enquiry' as an inductive qualitative method provided a transparent framework for recording, analyzing and representing the voices of forty-two

patients with faces. In this endeavour I have been inspired and guided by the work of those pioneers who saw narratives as a way of *'giving voice to'* and *'hearing the voices of'* the neglected. Although "I do not experience their experiences but I experience them as experiencing" (Munnell, 1976: p.47), in this I should at least expect the stories reverberating throughout this thesis to demonstrate the authenticity of their reality.

Doctor of Public Health (Dr PH) Integrating Statement

This research emerges from five years of studying a Dr PH research degree programme at the LSHTM. My education background began in community health studies many years ago and then in health services management and in public health (MPH). I have been in a health service management role in the NHS for over 12 years in London. I also hold several positions as a clinical facilitator in east London Primary Care and most recently as a public health strategist in pandemic Flu; health protection and TB strategy in the NHS Tower Hamlets. I enrolled in autumn 2005 as a part-time student on the Dr PH programme in order to reconcile my education with my clinical services management role. My original research interest was skeptical of the conventional public health research that assumes populations are static and their health outcomes measured invariably throughout time. My interest in this was to investigate the influences of population geographical mobility on TB control amongst the homeless in London. The lack of access to essential services, particularly for homeless with TB, and difficulties associated with being frequently mobile was a real spark of my research interest. During the years that followed, however, I feel my research interest evolved. This is largely due to my expanded learning and going through a number of units that the Dr PH programme offered me. The programme includes three compulsory units and three optional units and a Professional Attachment (PA) with a public health organization.

I began in the autumn 2005 with three core compulsory units of the Dr PH programme. The core compulsory units ran between September and December 2005. The evidence based public health practice comprises two compulsory units. The first unit is called evidence synthesis from research to improve public health practice. The second is evidence based public health policy to understand the processes of health policy development and the link between evidence and policy, the role of research on policy changes, barriers to evidence based policy and practice. The third compulsory unit is called leadership and management development and covered theories from the field organizational behaviour. It includes strategic and change management and personal leadership skills and public health leadership development. I learned not only how to undertake evidence synthesis, but it gave me an insight into how better to design research that is methodologically of sound quality where its evidence is assured. I also had the opportunity to review the evidence on directly observed treatment (DOT) for TB, aimed at homeless TB patients and how to present research evidence to influence policy. I learned how organizational theory help to better understand the role of public health organization, leadership and function to improve public health. The core compulsory units have provided me with background skills for professional attachment field practice.

In autumn 2006, I undertook a Professional Attachment (PA) at headquarters of the Health Protection Agency (HPA) in London. As one of the components of the Dr PH programme, I needed to learn the HPA's missions and its close quarter leadership functions and its contribution to public

health in the UK. Being part of the Organizational Development and Delivery Group (ODDG) / the Chief Executive Office in Holborn Gate - it was useful for me to be involved in 'port health work stream' and a membership of a project work group. The group was set up to formulate a policy advisory paper to the DH on effectiveness and efficiency of chest radiography as part of the DH port-entry TB screening policy. My project task was to undertake a systematic review of effectiveness and efficiency of chest radiography as a component of port entry TB screening aimed at asymptomatic migrants from high TB prevalent setting. Furthermore, my PA organizational research involved case study of (a) partnership between the HPA and the PCTS and LAs with port health function in England; (b) the HPA policy advisory functions to DH on the benefits of chest radiography to port entry TB screening policy. Employing case-study research, I was able to undertake face-to-face interviews with key policy informants from the HPA; Home Office and DH. I was able to learn about partnership through e-mail questionnaire survey with the HPUs and PCTs and LAs in England. It gave me a good background knowledge surrounding DH port-entry screening policy and the HPA's policy advisory role and barriers to effect change in policy, important ideas and background to current research project.

In spring 2006, I also undertook statistical methods in epidemiology optional unit in distance learning. The unit has significantly improved my understanding of the application of statistical epidemiology analysis using large population dataset from an epidemiological study. This involved acquiring knowledge and skills of STATA 9 statistical software, different types of epidemiological studies, statistical modeling and undertaking multivariate regression analysis. While I was on professional attachment, I undertook a further optional unit reviewing literature. The unit provided me with rigorous training and opportunity to transfer knowledge to professional attachment study and insight into the HPA policy advisory role. I consolidated my task of undertaking a review for the HPA project work group and the task of undertaking a review for the unit. I found good grounding and unique exposure and insight on research evidence contribution to policy advice. I also undertook the Proposal Development Unit (PD) optional unit while I was still on professional attachment. The unit has also provided me with opportunity to refine further my research focus by identifying gaps in knowledge associated with TB control in London.

My research began to shift from homeless to non-UK African and South Asian TB patients' healthcare seeking strategies. Recognizing the impact of social and cultural beliefs; living conditions (social inequalities); poverty and healthcare access experienced by minority patients offered me ample opportunities to learn about the link between theory and research. This unit made a particular contribution to this research where I began developing a research project proposal (called a Dr PH review document). Originally I intended to undertake two lines of investigation. (1) a quantitative research through follow up questionnaire survey with TB suspects referred from Gatwick and Heathrow port health units to HPUs to investigate factors determining their access to

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TB screening and services. (2) a qualitative research to understand the TB patients' experiences of access to TB diagnosis and treatment to understand factors determining their access to TB diagnosis. The unit was essential to my understanding about theories and models for designing research method and developing research proposal.

The Health Promotion Approaches and Practices Unit is another optional unit I have undertaken to be familiar with various health promotion theories, approaches and practices. The unit involved developing a practice manual of evidence-based appraisal of nine health promotion approaches, their strengths and weaknesses in tackling key public health priority areas. The motivational interviewing skill training, particularly client-centered interviewing, has given me good theoretical insight into the origin of client-centered approach in research and enhanced my understanding of case-centered approach of narrative interviews in this research.

The purpose of the current Dr PH research project is to help the student to learn about the role of research in public health practice (LSHTM, 2006/7). Although, like a PhD thesis, research must be high quality, examiners should consider that the duration of research by a full-time Dr PH student is expected to be undertaken in one year while the PhD student is expected to undertake it in three years (LSHTM, 2006/07). This is due to the six units and the Professional Attachment (PA) research involved in Dr PH programme which the PhD students may not be required to undertake. However, as I noted earlier, my expanded learning during the taught and professional components of my training has shaped my research project to its current form. My journey also highlights a number of areas of gaps that are of real research interest relating to current TB policy in London. Looking back, I have been over ambitious in what I intended to do. However, knowing now what is at the stake in undertaking this doctoral research, I had not appreciated the depth of the research that was required to answer my questions. To me, the process of undertaking this research has been a journey of intensive work that involved creating voluminous amount of rich data and managing to identify core themes to answer my research questions. I recognize that my understanding of qualitative research and my organizational skills have improved greatly. My flexible approach, committed attitude to my learning have been useful in many ways. I was able to relate to the contribution of the academic staff here in the school throughout the process of undertaking this research. I thank all those who taught me a great deal and helped me to keep going till the end.

Lemma Yilma
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ANNEX - 1

1. Research Ethics Committees (RECs) Approval
London School of Hygiene and Tropical Medicine REC - Letter
St Mary's Hospital REC - Letter

2. Research & Development Governance (Offices)
Guy's & St Thomas's NHS Trust Approval & Registration Letter
Newham University Teaching Hospital Approval & Registration Letter
Brent PCT Approval & Registration Letter
Lambeth PCT Approval & Registration Letter
Newham PCT Approval & Registration Letter

St Mary's REC
Research Ethics Committees
Room 4W/12, 4th Floor West
Charing Cross Hospital
Fulham Palace Road
London
W6 8RF

Telephone: 020 8846 7251
Facsimile: 020 8846 7280

28 January 2009

Mr Lemma Yilma
Research Degree Student
London School of Hygiene & Tropical Medicine
Centre of Population Studies (CPS)
50 Bedford Square
London
WC1 7HT

Dear Mr Yilma

Full title of study:	**An exploration of help-seeking experience of ethnic minority TB patients and the role of providers of TB services in London.**
REC reference number:	**08/H0712/145**

Thank you for your letter of 15 January 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Sub-Committee of the REC held on 26 January 2009. A list of the members who were present at the meeting is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). The favourable opinion for the study applies to all sites involved in the research. There is no requirement for other Local Research Ethics Committees to be informed or SSA to be carried out at each site.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study. Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date	
Covering Letter		17 November 2008	

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Protocol	1, Focus group discussion guide	19 November 2008	
Letter from sponsor, Ref: Indemnity cover		18 November 2008	
Peer Review		18 November 2008	
Andrew Sloggett's CV		20 November 2008	
Investigator CV		20 November 2008	
Participant Consent Form: Consent form for interview	1	19 November 2008	
Proposed Research Flow Chart	1	19 November 2008	
Provider Research Information sheet	1	19 November 2008	
Provider invitation letter	1	19 November 2008	
Letter of invitation to participant	1	19 November 2008	
Doctors information letter	1	19 November 2008	
Letters to directors	1	19 November 2008	
Practitioner invitation letter	1	19 November 2008	
Proposed Research Patient Interview Guide	1	19 November 2008	
Face-To -Face Interview Topics	1	19 November 2008	
Focus Group Interview Information	1	19 November 2008	
Doctor of Public Health Review Report		01 September 2008	
Response to Request for Further Information	letter from Mr Yilma	15 January 2009	
Participant Information Sheet: Patient	2	08 January 2009	
Application	with revisions included		
Provider information sheet	2	09 January 2009	
Doctor of Public Health Review Report	revised		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.The attached document "After ethical review –guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

*   Notifying substantial amendments
*   Progress and safety reports
*   Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

08/H0712/145	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

▮▮▮▮▮▮▮▮▮▮▮▮

Pp Mr Barrie Newton

Chairman

Email: Rosalind.Cooke@imperial.nhs.uk

Enclosures: "After ethical review – guidance for researchers"
Copy to: *Ms Penny Ireland R&D office*

St Mary's REC Attendance at Sub-Committee of the REC meeting on 26 January 2009
Committee Members:

Name	Profession	Present	Notes	
Mr Barrie Newton	Lay Chairman	Yes		
Dr Michael Schachter	Clinical Pharmacologist	Yes		

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Working with our partners for a healthier Brent
Applied Research Unit
Wembley Centre for Health & Care
116 Chaplin Road
Wembley
Middlesex
HA0 4UZ

Tel: 020 8795 6730/5
Fax: 020 8795 6737

email: ricky.banarsee@brentpct.nhs.uk

20 March2009

Mr Lemma Yilma
397 West Horne Avenue
Lee
London
SE12 9AB

Dear Lemma

Project Title	TB Patients experience of help and TB care delivery by providers
REC Ref	08/H0712/145
Chief Investigator	Lemma Yilma

Thank you for your assistance in providing the documentation for scrutiny of the proposal. I am satisfied that your proposal meets with the requirements of the Research Governance Framework (RGF). NHS Brent's Applied Research Unit has approved your proposal on the understanding that you adhere to the RG conditions attached. The end date of the project is listed as 30 August 2010. **Please note permission to start the study at NHS Brent is subject to receipt of a letter of access from its HR Department.**

2. **Approved Documents** *The documents received and approved were: -*

Documents	Date and version no.
Approval letter from St Mary's REC	29 Jan 2009
REC application form	20 Nov 2008
Site Specification Information Form	20 Nov 2008
Study protocol	15 Jan 2009 v2
Copy of signed declaration by Chief Investigator	17 Nov 2008
Copy of signed declaration by sponsors representative	20 Nov 2008
Sponsorship and indemnity letter from LSHTM	5 Feb 2009
Letter confirming peer review from Andrew Sloggett	18 Nov 2008
Participant Information Sheets	8 Jan 2009 v2
Provider Research Information Sheets	9 Jan 2009 v2
Consent Form for Interview	8 Jan 2009 v2
Proposed research Information Interview Guide	19 Nov 2008 v1

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Focus Group Discussion Information	19 Nov 2008 v1
Focus Group Discussion Guide	19 Nov 2008 v1
Practitioners of TB Services – Interview Topics	19 Nov 2008 v1
CV Lemma Yilma	undated

2.   Research Governance Requirement

From the information provided, the requirements of the Research Governance Framework have been satisfied in the following areas: -

Check list	1.1.1.1.1 (Yes/No or N/A)
The study has received independent peer review	Yes
From evidence provided the collection and storage of information for the study will be in accordance with the Data Protection Act (DPA 1998)	Yes
Use of PCT resources	Yes
CRB check requested	Yes

You must inform me, the approving Ethics Committee, and your sponsor within 48 hours of any serious adverse event(s) and within seven days of any non-serious adverse event(s).

You must respond promptly to requests for updating information from NHS Brent or the Northwest London Research Governance Unit and on completion of the study submit a copy of the NRES 'Declaration of the end of a study' form and a summary of the final report to the approving Ethics Committee and NHS Brent's Applied Research Unit.

Please do not hesitate to contact the Applied Research Unit (contact Don Macleod, (don.macleod@brentpct.nhs.uk), tel. 020 8795 6732 if you require further assistance.
With kind regards
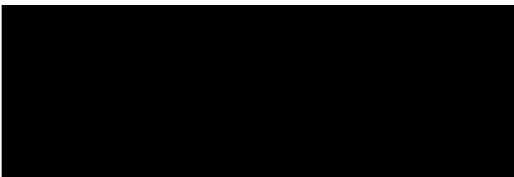
pp Ricky Banarsee, Director West London Primary Care Research Consortium/Applied Research Unit at Brent PCT

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Guy's and St Thomas' NHS

NHS Foundation Trust

Research & Development
Guy's & St Thomas' Foundation NHS Trust
3rd Floor Conybeare House
Guys Hospital
St Thomas Street
London SEI 9RT
Tel: 02071885731

07 July 2009

Dear Lemma

Title: TB patients experience of help and TB care delivery by providers
In accordance with the Department of Health's Research Governance Framework for Health and Social Care, all research projects taking place within the Trust must receive a favourable opinion from an ethics committee and approval from the Department of Research and Development (R&D) prior to commencement.
- Ethics number: 08/H0712/145
- Sponsor: London School of Hygiene and Tropical Medicine
- Funder: no funding
- End date: 3010812010
- Protocol: Version2 15/01/09
- Site: Guy's and ST Thomas' NHS Foundation Trust
- R&D approval Date: 7th July 2009

R&D have reviewed the documentation submitted for this project and I am pleased to inform you that we are approving the work to proceed within Guy's and St Thomas' NHS Foundation Trust and has been allocated the Trust R&D registration number RJ1 09/N097.Please quote the R&D registration number in any communications with the R&D Department regarding your project.
Conditions of Approval:
- The principal investigator must notify R&D of the actual end date of the project.
- The Principal Investigator is responsible for ensuring that Data Protection
  procedures are observed throughout the course of the project.
- The project must follow the agreed protocol and be conducted in accordance with all Trust
  Policies and Procedures especially those relating to research and data management.
- R&D must be notified of any changes to the protocol prior to implementation.
- Please submit a copy of the progress report on the anniversary of the Ethics favourable opinion
  (18 April through the CI)
If appropriate it is recommended that you register with the Current Controlled Trials website; http://isrctn.org/

Please ensure that you are aware of your responsibilities in relation to The Data Protection Act 1998, NHS Confidentiality Code of Practice, NHS Caldicott Report and Caldicott Guardians, the Human Tissue Act 2004, Good Clinical Practice, the NHS Research Governance Framework for Health and Social Care, Second Edition April 2005 and any further legislation released during the time of this study.
Members of the research team must have appropriate substantive or honorary contracts with the Trust prior to the study commencing. Any additional researchers who join the study at a later stage must also hold a suitable contract.

If the project is a clinical trial under the European Union Clinical Trials Directive the following must also be complied with:
1. The EU Directive on Clinical Trials (Directive 2001/20/EC) and UK's implementation of the
   Directive: The Medicines for Human Use (Clinical Trials) Regulations 2004;
2. The EU Directive on Principles and Guidelines for Good Clinical Practice (EU Commission
   Directive 2005/28/EC); and UK's implementation of the Directive: The Medicines for Human Use
   (Clinical Trials) Amendment Regulations 2006;

Amendments
Please ensure that you submit a copy of any amendments made to this study to the R&D Department.

Annual Report
It is obligatory that an annual report is submitted by the Chief Investigator to the research ethics committee, and we ask that a copy is sent to the R&D Department. The yearly period commences from the date of receiving a favourable opinion from the ethics committee.

Should you require any further information please do not hesitate to contact us.

In line with the Research Governance Framework, your project may be randomly selected for monitoring for compliance against the standards set out in the Framework. For information, the Trust's process for the monitoring of projects and the associated guidance is available from the Trust's intranet or on request from the R&D Department. You will be notified by the R&D Department if and when your project has been selected as part of the monitoring process. No action is needed until that time.

Many thanks for registering your research project

Yours faithfully

Karen Ignatian
R&D Delivery Manager

cc. Chief Investigator
cc. Sponsor

NHS

Southwark PCT
Public Health Department
2nd floor Woodmill Building
Neckinger
London, SE16 3QN
Tel: 020 7525 0289
Fax: 020 7525 0318
email: anne.grant@southwarkpct.nhs.uk
www.researchdevelopmentcentre.nhs.uk

Mr Lemma Yilma
Research Student
LSHTM
Centre of Population studies (CPS)
50 Bedford Square
London
WC1 7HT

24 January 2012

Dear Mr Yimla

**Project Title: An exploration of help-seeking experience of ethnic minority TB patients
and the role of providers of TB services in London
R & D Reference: RDLAM 457**

Thank you for your assistance providing the documentation for the scrutiny of this project.

I am satisfied that your study meets with the requirements of the Research Governance
Framework. It has been approved by the research lead for the respective Trust.

Approval is given on behalf of Lambeth Primary Care Trust on the understanding that you
adhere to the conditions on the attached document. The end date of the project is listed as 30th
August 2010.

If you require any further information, please contact Dr Anne Grant on 020 7525 0289.

Yours sincerely

Hiten Dodhia
Consultant in Public Health and R&D lead for Lambeth PCT
Chair of the Research Management Group for
Greenwich, Lambeth, Lewisham & Southwark PCTs

Newham University Hospital **NHS**

NHS Trust

Mr Lemma Yilma
Research Degree Student
London School of Hygiene and
Tropical Medicine
Centre of Population Studies
50 Bedford Square
London
WC1 7HT

Research & Development Office,
c/o Academic Centre,
NEWHAM GENERAL HOSPITAL
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Tel: 0207 363 8923 / 9266 Direct Line
Fax 020 7363 9463 external (3463 internal)
Email joanne.morris@newhamhealth.nhs.uk
doreen.ampomahasiedu@newhamhealth.nhs.uk
shanti.vijayaraghavan@newhamhealth.nhs.uk
Dr Shanti Vijayaraghavan, Director of Research &
Development (R&D).
Dr Joanne Morris, R&D Manager.
Ms Doreen Ampomah - Asiedu, R&D Co-ordinator

Dear Lemma,
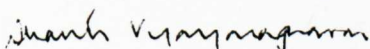
Re: An exploration of help-seeking experience of ethinic minority TB patients and
the role of providers of TB services in London
R&D ID: 2009/12

Thank you for providing us with information concerning the above study. This letter is to
confirm that the Trust has approved the study and, is providing indemnity to cover the
involvement of Newham University Hospital NHS Trust staff and any staff with an honorary
contract at Newham University Hospital NHS Trust for purposes of the study. The approval
is provided on the understanding that the London School of Hygiene and Tropical Medicine
has agreed to be the official SPONSOR for the study and has ensured adequate indemnity
and monitoring arrangements. In addition, as the Chief Investigator, you must ensure
adherence to the ethically approved study protocol and responsibilities outlined in the
'Research Governance Framework for Health and Social Care', 2nd Edition, DH April 2005.
http://www.dh.gov.uk/en/Researchanddevelopment/A-Z/Researchgovernance/DH_4002112

Please inform us if your project is amended and you need to re-submit it to the Ethics
Committee **and when the project terminates**. This is necessary to ensure that your
approval/indemnity is valid and also helps the office to maintain up to date records. Should
any untoward events or incidents occur then it is essential that you immediately contact the
Trust Risk Unit (020 7055 5792/ 5793) and the R & D Office at Newham. We would also ask
that you keep us informed of any publications or final reports that are produced as a result of
the research.

Please do not hesitate to contact either Dr. Joanne Morris (R&D Manager) on 020 7363
8923 or myself on 020 7363 8454 if you have any further questions.

With best wishes for the study,

Dr Shanti Vijayaraghavan,
Director of R&D

cc Dr Geoff Packe (Respiratory Medicine), Rehana Adil (Business Manager – Acute Care);
Andy Sloggett (Academic supervisor).

ANNEX -2

1. Exploratory Pilot Research

Exploration of Experience of African and Asian TB patients in London
Narrative Research and Thematic Analysis

(Full-Report)

Exploration of experience of African and Asian TB patients in London

Pilot Report

Lemma Yilma
July 2009

Supervisors:
Andy Sloggett and
Isabelle Lange

London School of Hygiene and Tropical Medicine

Centre of Population Studies
University of London
50 Bedford Square
London WC1E 7HT
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🖷 (00) +44 (0)20 7323 0638

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Exploration of experience of African and Asian TB patients in London
A Narrative Thematic Analysis

A Pilot Study

Project Summary

The exploratory pilot research was undertaken to understand key issues involved with TB patients' experiences of illness and the medical care in order to identify key question for further research and also to test the feasibility of a narrative method in research with TB patients. The report will discuss the outcome of this pilot, one key theme emerging as most common experiences of the pilot participants' and its implication for future research.

Method: the pilot consists of a qualitative narrative research undertaken in three chest clinics in London. It is based on oral illness stories gathered through in-depth qualitative interviews with ten African and South Asian (volunteers) TB patients. The analysis of narratives from the ten interviewees involved data collection with the aid of Digital Voice Recorder. The verbatim transcripts were then arranged using NVivo8 software and manual searching for themes.

Result: the pilot has provided the opportunity to test the feasibility of narrative method for understanding the hidden perspectives of TB patients for the main research. The key theme emerging from the stories told by most interviewees is about their experiences of miscommunication with their professionals during their illness contributed to delayed pathways to diagnosis and TB treatment.

Introduction

This exploratory pilot research has been undertaken to understand key issues associated with TB patients' experiences of illness and medical care and seeks to reformulate the proposed research question with TB patients in London.

Tuberculosis is one of the leading causes of death and chronic infection worldwide. In the UK since the late 1980's the number of cases of the disease has been increasing, particularly in black African and South Asian ethnic minority populations, (1). The background section of the report will highlight several factors which have been associated with the increase in an individual's vulnerability (susceptibility) to TB and their ability to take appropriate action. Similarly the review will also look into health care related factors hindering the patients' pathways to health care diagnostic and treatment services, particularly in these marginalized population groups. Despite wide research interest to understand factors limiting patients' health care seeking, there is little emphasis given in research to understand the patients' experiences of pathways to TB diagnosis and treatment centred on their descriptions of events.

As a result, it appears that little is known from published studies in the UK as a whole to answer the question of "What is it like experiencing illness for African and South Asian with TB?" Key answers to this question will be useful for understanding the commonalities and differences of patients' experience of TB illness recognition, influences of family, and experience of community and health care professionals. The report will discuss the outcome of this exploratory pilot, one key theme emerging as most important for further research that is relevant to TB patients, public health practice and TB policy in London.

This report is divided in two parts:

The first section of the report will present the exploratory pilot research findings: background, method and discussion of the pilot research. In the second part, the report will provide a short summary of the implication of pilot research findings, the main research question, proposed methodology and data analysis and a topic guide for the main research.

1. Background

Patients' experience and their judgment of many aspects of their health and social care have been widely acknowledged to reflect key service quality indicators which are increasingly becoming core to a number of DH recent health care policy incentives, (2). This policy guidance has been designed to ensure better care for all patients in primary care and hospital care services.

In the arena of health care, particularly in TB control, there has been a heightened emphasis on public education about TB, improving fast access to TB services, patients' experiences as part of local care delivery, (3) and patient-centered care, (4). There is no doubt that amongst the key drivers to these efforts is an increasing TB notifications rate particularly in African and South Asian populations, accounting for more than 40% of all reported cases in the UK as a whole, (5).

There is, however, little emphasis in research into understanding the experience of TB patients in the UK. Thus far, most research has focused on demographic differences contributory to delaying TB diagnosis and treatment associated with the patients or their health care providers. In more recent years, however, few qualitative researchers have attempted to explore individuals' accounts of factors determining their access to health care services. The section that follows will present a more focused and detailed review of published literature in the UK; selected from previous reviews undertaken.

1.1   Literature Reviews

Several studies world wide documented that early diagnosis and starting treatment within four weeks of manifestations of symptoms are key to TB control. Amongst studies in the UK, a study by Roger et al investigated delay in seeking health care for TB diagnosis. The evidence gathered by these researchers was based on clinical surveillance data and did not gather health service contact information from patients, (6). Based on their findings, researchers reported that being of white ethnic origin and female was associated with delaying TB diagnosis.

However, one follow up cohort study by Paynter et al has found delays that were linked to health care services. The researchers found that amongst 46 patients they followed up, 37 patients who sought care from their GPs had longer delays before TB diagnosis, (median delay 49 days) than nine patients who sought care from A&E before TB diagnosis (median delay 4 days). The researchers also reported that those patients who contacted their GPs first had previously delayed less (30 days - median delay) than those who contacted the A&E first who had previously delayed substantially more (54 days - median delay). From reported data it was clear that the nine patients who sought care from A&E first were migrants who were born in high TB prevalent countries and had delayed more than the 37 patients who sought care from their GPs. The researchers' conclusion was that there was a considerable delay associated with referral pathways from GPs to diagnostic services (health service related delay). As discussed above, it was also apparent that patients who sought care in A&E first had delayed longer than those who sought care from their GPs, (patient related factor), (7). Taken together, it is clear that delay is associated with the patients and also health care services. Although the evidence is useful in highlighting differences of patients' pathways to health care and to TB diagnosis, factors determining patients' decisions on when to seek medical help and choices of health care could have been more informative. The evidence from these studies is limited in revealing the underlying factors determining patients' pathways to TB diagnosis. For the purpose of this review, their limitations are clear around data gathered to explain the actual processes shaping patients perception of their illness and their decisions on health care utilizations. Few qualitative studies in the UK explored various aspects of TB patients' experiences of pathways to TB diagnosis. The reviews of these studies are discussed below.

A study by Nnoaham et al (8) highlighted significant differences in delaying TB diagnosis ranging from two weeks up to forty weeks among the 16 African patients they have interviewed. These researchers identified several factors that may account for these differences. Amongst factors found are: perceptions of symptoms, misconceptions concerning disease etiology, symptom misinterpretation and linking symptoms to food poisoning and heavy workloads and denial of diagnosis. Furthermore, delays were also associated with the health professionals' failure to diagnose illness early, patients' experiences of stigma by health care staff – particularly associated with the infection isolation practices, presence of stigma involving close family members, and also HIV cross stigmatization of TB in the community. The study's findings suggest other influences beyond the patient and health care services involving their family and the wider community. While illness misinterpretation, denial and stigma could account for reported delay, in the 9 of the 16 patients interviewed who had delayed over four weeks before health care contact, their experience of stigma and reported delay is not sufficiently described to demonstrate associations, (8).

In their exploratory study, researchers in south east Wales investigated the process of TB diagnosis in primary care, (9). The research involved 17 TB patients and 16 GPs. These researchers explored the patients' health status prior to diagnosis, their contact with health services and their views on TB diagnosis services. They also investigated GPs' accounts of the diagnostic processes for their patients and their views on specific cases drawn from their patients' stories. The most important finding concerned the patients' experiences of pathways to TB diagnosis involving numerous contacts made by the patients to their GPs. This was consistent across all patients interviewed where the majority of these patients visited their GPs from 2 to 4 times before referral to TB diagnosis. The authors' findings in relation to patients' accounts revealed that: lack of continuity of patient care by GPs and the GPs' consultations did not seek to identify the patients' health concerns. Most patients felt that they were not listened to; their expressed concerns about the risk

of TB were not taken seriously by their GPs resulting in misunderstandings between the patients and their GPs.

In summary, evidence from the review seems to indicate that TB patients' experiences of pathways to TB diagnosis appear to involve four main areas. These factors are related to illness experienced by the patients themselves 'the self', to influences of family and close contacts, to the wider community and also to the health care services. From studies reviewed, the issues also highlighted by researchers' interest into factors associated with delay spans the continuum from illness behaviour – interpretation of illness, *'health seeking'* involving family, friends the processes on the one hand, and the end point (utilization of the formal system) medical care from health professionals *'health care seeking behavior'* on the other, (10). While the above illustrates complex issues involving the continuum, it appears that there is limited knowledge from published studies in the UK specifically addressing the experiences of illness for African and South Asians with TB. Focusing on their experiences of illness is useful to understand the commonalities and differences which will yield insight into the selection of an important question for research.

1.2   Purpose

The purpose of this pilot is to investigate the experience of ethnic minority TB patients centered on patients' stories and descriptions of the context in which their experiences were shaped. Discovering differences or commonalities of patients' experiences from their stories will help to modify the current research working title and choose a research question for more focused field research in the remaining part of field research. The purpose of this pilot study is twofold:

1   To investigate the experience of African and South Asian TB patients in London.
2   To identify a key theme from patients' stories and develop a research question for further study

Given the current DH health care agenda gives emphasis to patients' experiences of health care, undertaking this research with patients' experiences of pathways to TB diagnosis justifies the rationale for undertaking this exploratory pilot.

2   Method

Interpretative narrative enquiry[13] is the methodological foundation for this pilot research, (11). This approach has been effectively applied in research where the focus of enquiry is a case-centred or individual TB patient - the narrator of his/her past experience, *(11, p.11-13)*. Narrative research method is a subfield in qualitative inquiry and a new development in social sciences which can be adapted and combined to a range of theories and epistemologies not confined to the boundaries of any one discipline – and cross disciplinary, (11, p.14-7) research method. The method was useful to the goal of this pilot study which sought to generate detailed accounts of TB patients' experiences through discrete open questions and closed (fixed response) questions, *(11, p.23)*.

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[13] Interpretive Narrative Enquiry is defined as interpretive research, using "storytelling" or "Narrative Inquiry," which does not attempt to predefine independent variables and dependent variables, but acknowledges context and seeks to "understand phenomena through the meanings that people assign to them. According to Riessman the narrative approach in human science research recognizes research participants as interpretive of their stories and interpretive accounts also developed by the researcher based on his/her field work observations (a story about stories), *(11, p6)*.

2.1 Ethics

Favourable ethical opinion has been obtained from the St Mary's and the LSHTM Research Ethics Committees. The research has been registered with the Brent, Newham, and Lambeth PCTs. Research approval has been obtained from the R&D and governance unit, Guys and St Thomas' NHS Trust & processing approval with the Newham NHS hospital Trusts. In all these sectors, lead chest physicians have given full permission for the researcher to conduct the pilot and the main research with their patients including the use of clinic facilities for interview purposes, depending on availability of rooms.

2.2 Study Settings, Participants Selection Procedure

This pilot study began in May in three boroughs of London. Prior to starting the pilot (in April), a standard letter with accompanying short project summary, ethical approval letters sent to six chest physicians in four hospitals: Central Middlesex, Northwick Park Hospital, Guy's & St Thomas' hospital and Newham Hospital NHS Trust. Prearranged face to face meetings were held with physicians to discuss the purpose of the pilot and study procedure of the patient selection criteria.

After obtaining permission from chest physicians, the researcher began field work on 24th April at Willesden clinic and 27th April in St Thomas Hospital and Shrewsbury Rd clinic. On each clinic site, meetings with nurses achieved and explained the purpose of the pilot and patients' selection procedures.

Table 1   Pilot participants' Demography, Types of TB and Dates of Health Care Contact

Patient	1	2	3	4	5	6	7	8	9	10
Age	24	27	34	28	29	51	41	18	18	40
Sex	M	F	M	M	M	M	M	F	F	F
Birth place	Pakistan	India	Pakistan	Nepal	India	Ethiopia	Ethiopia	UK	Somalia	Somalia
Known TB Contact	Cousins Pakistan	Not known	Friend in London	Live with TB case	Not known	Not known	Not known	Not known	Friend London	Not Known
Type of TB	PTb	GTb	GTb	OTb	PTb.	PTb	PTb.	PTb	STb	ATb & GTb
First HC Contact	GP	Private	GP	Private	GP	A&E	A&E	GP	GP	GP
Date of HC contact	Dec, 08	Feb, 09	Feb, 09	Mar, 09	May,08	Dec, 08	Dec, 08	May,08	Apr, 09	Oct, 08
Diagnosis	May, 09	Feb, 09	May, 09	Mar, 09	Feb, 09	Dec, 08	Dec, 08	Jun, 08	May, 09	Feb, 09
Treatment started	May, 09	April, 09	May, 09	Mar, 09	Feb, 09	Dec, 08	Dec, 08	Jun, 08	May, 09	Feb, 09

Keys:

PTb – pulmonary TB	ATb- abdominal (Pritoneal) TB	GTb - Glandular TB
STb – TB in Spines	OTb – TB in the retina (eye)	HC- Health care
Pt. – patient		

The pilot was designed to recruit two volunteers from one chest clinic in each borough for a face-to-face qualitative interview. The clinicians' support was first sought in the selection of participants. Most participants were foreign born: nine of the ten patients were interviewed. Four patients were female and six were male; 5 with pulmonary TB (PTb) and five patients with non Pulmonary TB (NPTb). Only one patient was born in the UK and of African ethnic origin. Amongst the foreign born participants; four volunteers were born in Africa and five patients born in South Asia. (see Table 1)

2.3   Data Collection

The research employed a semi-structured patient centred interview guide designed to explore the patients' experiences of illness 'self awareness', the influences of their family or close contacts, others in the community and also their experiences of the health care professionals. Each interviewee began with a brief description of their health prior to illness, their place of birth, family status, occupation and active life prior to illness.

   Almost all participants narrated their experience of illness leading to the discovery of their diagnosis. Following this, each interviewee ran through their illness story uninterrupted. Subsequent questions guided the interviewee to reflect on the influence of their family by probing and prompting to explore the patients' experiences of those who are close to them. Where appropriate, explanations were asked on what was experienced and the context of the patient experience and meaning it had to the patient. Similarly, their experiences with other contacts at work, college, friends and community members. Finally, events leading to their diagnosis and the pathways to health care chronology of contacts and processes and experiences of medical help in general.

2.4   Interview Results and Analysis

Data from the ten interviewees were collected with the aid of Digital Voice Recorder *Olympus WS-331M*. Analyses of the verbatim transcripts for all ten patients were achieved using NVivo8 and also manual searching for themes.

   Applying Gee's method of narrative transcription giving title to each category (stanza - thematic point) and deleting the interviewer prompts, has aided data interpretations but also presents the narrative as if the story arose full blown within 'the self' from each patient, *(11, p35)*. The initial coding involved transporting the interviewee's prearranged transcripts onto NVivo8 and running an auto code command produced numerous child nodes (contain themes) under the tree node coded as experience. Going through each child node and deleting nodes without textual information and giving topical code to each child node that belongs to a particular experience derived from the story. This process of examining each child node and giving topical code helped to identify themes in a step by step process covering the entire transcripts for each interviewee. During a further analysis, the codes were renamed, clustered, and grouped into broad categories of patients' experiences. *(see Appendix 4)*

      The manual searching for themes reading and re-reading transcripts and listing and grouping expressions in order to determine the expressions that highlight the interviewee's main experience, *(12, p.130)*. Key word, phrase, paragraph of expressions linked to patients' experience were cut and pasted and clustered into categories to identify key themes. Below is a summary list of categories of patients experiences derived from all 10 interviewees' verbatim transcripts. Detailed analysis of data or anonymized quotes will be made available. *(see Table 2)*

Table 2 Main categories of themes and patients' experiences.

Categories of themes	Invariant constituents of patients' experiences
1. Miscommunication[14] of TB risk in community: Insufficient knowledge & misinterpretation of symptoms. • *Perceptions of illness linking it to recent events.* • *Thinking and reflection on past remembering contact with TB case.*	1 *Experience of occasional dry cough and irritations of the throats thinking it will go away, (pt.6)* 2 *Thinking of the shoulder pain associated with work (papers delivery), (pt.1)* 3 *pain involving chest & shoulder muscles – GP said muscular pain , (pt. 8)* 4 *thought of cough related to cold weather conditions, (pt.5)* 5 *changing body image connected to the swollen gland on the neck , (pt.2)* 6 *thinking insect bites may have caused the neck swelling, (pt 3)* 7 *over work have contributed to deterioration of visibility on eye, (pt.4)* 8 *gradual pain on the back and weakness increases by each day, (pt.9)* 9 *Illness transitions, acute pneumonia abroad on return to UK hosp. admission & TB diagnosis – thinking TB risk on a flight to UK, (pt.7).* 10 *Thinking indigestion may have caused stomach pain and swelling, (pt.10)* 11 *Not knowing anyone with TB and it's frightening feelings about causes, (pt.6)* 12 *Remembering of living and caring with a friend with pulmonary TB,(pt.8)* 13 *Remembering visiting a friend who had PTb, and not realizing the risk.(pt.3)* 14 *Memorizing past visits to two cousins died of TB in the last 5 years, (pt.1)* 15 *Feeling well during the day and ill at night feeling a sense of wellness, (pt.1,6,8,10)* 16 *Experience of illness at night is different from day time, (pt.2,8)*
2. Health care seeking decisions for medical help: • *choosing options of medical help.* • *path to diagnosis personal choice & preferences.* • *remembering the significance of family and friends influences*	1. *Experiencing fever in the cold winter night and sleep disturbances advice by household members to seek medical help, (pt1)* 2. *Advice from friend and family members to seek medical help from GP.* 3. *Illness and worries of the family members and friends.* 4. *Receiving night visits offer of home remedies from people sharing home* 5. *Consulting to a friend who offered antibiotics that helps with pain* 6. *Not registered with a GP A&E doctor referred to ENT went to private Dr* 7. *Knowing about a GP who was delaying referral to a friend who had TB,* 8. *Sought care from A&E, when noticing blood in the cough, (pt.6)* 9. *Severe illness on eye choosing private care rather than GP.* 10. *Severe Illness at the weekend led to seek care from A&E Dr who thought it was TB wrote letter to the GP to refer, (pt.1)* 11. *A mother who felt unsupported by her GP decided to seek care from A&E for a daughter, (pt.8)* 12. *Being informed by the GP it's flu needed to take pain killers and rest, (pt.5)* 13. *Experiencing sever pain at night needing emergency admission a GP told the patient to go to the walking centre, (pt5).* 14. *Consulted with family before going to the GP, (most)* 15. *Irritating pain on my neck a friend said I should go to my GP , (pt.9)* 16. *Dry cough and cough with blood at night choosing care from A&E., (pt.6)* 17. *Searching for a private Dr who understands language and culture, (pt.5 &8)* 18. *Being critically ill needing hospital care life saving surgical intervention, (pt.7).* 19. *Missing emotional and psychological support of family bad relationship, hurt and emptiness in his life, (pt.7).* 20. *Living with supportive friends and neighbors, (pt.1,2,4,5,8,9,10)*

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[14] Miscommunication: is a theme of health care seeking behavior that describes the failure to communicate adequately, this is evident in the stories told by patients - *lack of listening: lack of information: assuming: confusion to patients associated with the lack of understanding about TB transmission mechanisms creating* misinterpretation and misunderstandings [Mortensen, 1997]. Miscommunication concerns the very elusive, enigmatic and inscrutable aspects of communication and the "maze of messages" Cited in *Anolli, Ciceri and Riva (Eds p37.)*

3.Feelings and memories of medical consultations with GPs and miscommunication of illness experienced	1. Being on pain killers and symptomatic treatment for long period,(pt.1, 3,5,8,10) 2. No benefit from the GP, could not wait, sought help from the A&E instead, (pt.1,5 and 8) 3. Informing all symptoms of TB but GP still not thinking it was TB, (pt.1,3,5,8,10) 4. Being informed by the A&E doctor who advised a GP to refer, (pt.1 and 3) 5. A positive experience of consulting with a GP who knows about TB, (pt.9) 6. Hearing community perception of delaying treatment by GPs', (pt.9) 7. Telling the GP all TB symptoms, swollen abdomen GP offered a test for pregnancy, (pt.10). 8. Telling the GP that I had all TB symptoms and asking him to refer me to chest clinic and he did not think I had TB.(pt.1 and 5) 9. Knowing a GP who did not refer or send private Dr report to a chest clinic 10. Feelings about GP consultations over referral for TB test, (pt.1, 3,5,8,10) 11. Learning from a friend ill with TB his GP did not refer only gave painkillers, (pt.4) 12. Feelings about consultation with impolite and uncommunicative GP,(pt.2, & 8) 13. Feelings about unnecessary waiting for too long and making illness worse,(pt. 1,5,10) 14. Being worried about lost test results and chest clinic doctor cannot help without the TB test delaying start of treatment, (pt.2) 15. Consulting with a chest clinic doctor who did not carry out the test needed being asked to return for the test, (pt.2). 16. Knowing a GP who knows about TB and test procedure, (pt.9)
4. The path to TB diagnosis, uncertainty, worry, anxiety and shock. • Feelings about miscommunication of test results, lack of information and medical help from professionals.	1. Feelings about discomfort of going through lots of tests procedures, (pt.3,5,10) 2. Had no choice or information over test procedures in hospital, (pt.8) 3. Feelings about the care in an isolation unit in hospital, (pt.8) 4. A sense of feelings safe, in the care of hardworking hospital staff,(pt.1,5,6,7,10) 5. worsening stomach pain and swollen glands undergoing several tests, 9pt.2,10) 6. Worry over long hospital appointment after GP referral, (pt.5,10) 7. Undergoing repeat test procedures no information results not communicated by the GP, (pt.2, 8). 8. Being uncertain of the outcome of diagnosis and constant anxiety, (pt.2,3,4) 9. Informed of likely causes it could be TB, cancer or severe eye condition, (pt.4) 10. A sense relief the test outcome was TB and not cancer, (pt.2,3) 11. Relieved it is not severe eye complications, (pt.4). 12. Feelings of misunderstanding of what was happening and being left alone in an isolation unit in hospital, (pt.8) 13. Subjected to lots of diagnostic tests and had no choice or information, (pt.8) 14. Unsympathetic care alienation led to crying, embarrassment and panic, (pt.8) 15. Bad memory of consultation with the GP following A&E contact, (pt.8). 16. Admitted in isolation, informed of hospital procedures, (pt.4,6, and 7) 17. Knowing it was TB had to wait at home for transfer of private report, (pt.2) 18. Delaying treatment, health care systems 'miscommunication' of test results. (pt.2). 19. Feelings about the GP who ignored a letter from the private Dr, (pt.2) 20. Consulting with a GP who was reluctant to refer to chest clinic, (pt.1,2,3,5,8) 21. Delay linked to missing the opportunity to test by the chest clinic Dr, (pt.2) 22. Missing private test report and repeat tests after lengthy waiting at home, (pt.2).
5. Feelings about the pre/ post diagnosis experiences of medical help. • Insufficient information on medical care. • Worries about illness symptoms and treatment effect, demand for information	1. Feeling happy knowing what it was and TB treatment is going to start, (pt.1,5,10) 2. A sense of shock and confusion, how it has occurred, (pt.1,2,3,6,7,8,10) 3. A sense of happiness after long waiting with the pain killers at the GP, (pt.1,5,10) 4. Experience of going through painful diagnostic tests, (pt.3,5,8,10) 5. Difficult but getting used to TB treatment, (pt.1,2,4,5,6,7,8,9,10) 6. Experience of problem in getting referral from GPs, (7. Feeling a sense of wellness and normal again after starting the treatment 8. A sense of commitment to adhere to strict treatment procedures. 9. Changing negative perceptions about taking tablets, (pt,1,2,5,7,8,9) 10. Feeling committed on taking tablets to restore health.(ALL) 11. Support from family in reminding medication and hospital appointments, (pt.8,9) 12. Feeling burning sensation and severe headaches when taking medication, (pt.7) 13. Insufficient information on TB from health professionals, (pt.5,7,8)

	14. A lack of understanding of the medical language in hospital, (pt.5,7,8), 15. Concerns about future risk of infection with TB, (pt.8). 16. The lack of understanding of treatment effect on symptoms experienced, (pt.5,7) 17. Searching the internet, or seeking advice from a friend, (pt.5 and 7) 18. Being told by the phone to attend chest clinic by the GP, (pt.3) 19. Feelings about not obtaining information on test results from GPs, (pt.3,8) 20. A sense of worries why the treatment is not working for cough, (pt.5)
6. Impact of illness on work, study and relationships • *concerns about risk to others* • *limiting contact, and none disclosure of illness* • *miscommunication of TB risk*	1. Considered going back to home country, (pt.1) 2. Reflection on the consequences of continuing relations as before, (All) 3. Consulting with a friend who knows how to take precautions to avoid risk to others in a household, (pt.2) 4. Discovery of a close friend who was diagnosed with TB, (pt.8) 5. Working out and thinking to tackle problems of risk of infection to others, (pt.1,2,5,7,) 6. Uncomfortable feelings and worries about sitting next to passengers on the public bus, (pt.5) 7. Being asked by professionals to give details of all close contacts, (pt.1.2,3,5,6,7,8). 8. Worry about how others feel about being at risk from being close contact. 9. Informed about the risk to others by health professionals. 10. After being diagnosed family and friends needed a TB test. 11. No experience of avoidance by those who are close or others, (all patients) 12. Being told by a doctor to avoid contact with everyone for six months, (pt.7) 13. Disclosure of illness worry about 'stress' and 'anxiety' to family abroad, (pt.1,2,5) 14. Choosing who to tell source of emotional and psychological support. (pt.1,2) 15. Illness caused disruption of studies, and work commitments, (pt.1,8,9), 16. Being told not to resume a college placement before treatment, (pt.9). 17. A friend advising that coughing and being ill at work may upset customers, (pt.5) 18. In a position of having to make decision to quit, job, (pt.5) 19. A sense of relief after two weeks treatment no risk to others, (pt.1,2,5,6,8) 20. Continuing as normal giving thought to and worry about being a risk to others. 21. Being asked the name of close friends and school details, (pt.1,8) 22. Experiencing of illness limits ability to function normally, (pt.1,2,4,5,7,8,9,10)

4. Discussion

This exploratory pilot project provides useful information and an insight into the experiences of the African and South Asian TB patients in London. The research participants, despite differences in their types of TB and illness manifestations and experiences, do share commonalities of certain experiences - particularly their experiences of positive support from their family and close friends and the difficulties surrounding their medical help. The purpose of the pilot was to explore the African and South Asian TB patients' experiences and to identify a key emerging theme from the interviewees' stories to develop a question for further research. The pilot also provided useful information for planning the main research, particularly in relation to problems that emerged during the pilot.

Throughout this undertaking, it was clear that the participant centred approach to using an exploratory interview created an opportunity for each interviewee to talk freely and openly. It was clear also that all patients were able to recall chronology of events they had experienced and actions they had taken despite difficulties in remembering specific dates and time. The interview prompts have been useful to pose questions to interviewees in order to reveal any inconsistency regarding the content, time period or chronology of events they have experienced. The sub-sections of the discussion that follows will present the main themes discovered from the interviewees' stories and highlight the implication for further research.

4.1 Misinterpretation of TB symptoms – miscommunication of risk

The study reveals that most of the patients' awareness and interpretation of TB symptoms involved perception of the likely causes of illness rather than making the link to previous exposure to TB. When the interviewees began to reflect on the past, most patients were able to recall their previous contact with TB cases but showed no understanding of how they may have been at risk of infection. The length of time since their contact with TB patients not only contributed to their low perception of risk of TB infection, but also seemed to highlight the presence of a lack of understanding of the disease transmission mechanisms in the community. This highlights the lack of public education on TB particularly for these participants who are part of population groups who are at most risk of TB infection in London. Researchers argue that lack of knowledge of TB and misinterpretation of illness cannot be these patients' fault - but in fact it is the manifestations of failure to communicate risk on the part of the providers of care.

Their illness experiences were mostly gradual and in onset but for some the onset involved an acute illness or illness symptoms and pain which was perceived by the interviewees as needing hospital care (pt.4 and 7). Their awareness of TB symptoms and interpretations appear to suggest a lack of understanding of disease manifestations. The study findings echo previous research findings of the misinterpretation of TB symptoms, (8, and 9). For two patients, (pt. 1 and 5) with pulmonary TB the interpretation of symptoms during consultations with their GPs was a real frustration. As their story reveals, even though they had informed their GPs that they had all the symptoms of TB and demanded referral to a chest clinic, their GPs did not take their concerns seriously.

4.2 Medical consultations – miscommunication with GPs

Patients' accounts also highlighted how their illness experience and decision to seek medical help involved those close to them, their families and friends. It was clear that the support from family and friends and also the patients close networks created a supportive environment in their search for treatment. In deciding where to seek care, the advice of family and friends had been positive towards medical help. One patient refused to seek medical help, but her mother insisted on her consulting with her GP, (pt.8). Five patients, (pt.1,3,5,9 and 10) consulted with family members and friends in their decision to consult with their GPs, and one other, (pt.4) who was advised by his friend not to consult with GP for his illness, manifested by poor visibility of his left eye.

Three patients, (pt.2, 4, and 6) also felt that seeking medical help from their GPs was unhelpful and one, (pt.2) who was not registered with a GP prior to her illness - did not consider it as a real need to register with a GP at the time. It was clear from her story that she regarded GPs as too lengthy and time consuming for her needs. It was apparent that most patients, (pt. 1,3,5,8,10) who sought care from their GPs experienced treatments that they thought unhelpful, and as a result, they had lengthy periods waiting with pain, severity of illness and many visits to their GPs. Three of them sought care from A&E, (pt.1, 5 and 8) by themselves and two were referred by their GPs, (pt.3 and 10). Of the six patients who contacted their GPs, only one patient, (pt. 9) with spinal TB felt her GP referred her directly to a chest clinic indicating a likely TB diagnosis which was later found to be accurate. Almost all of these patients reported experience of miscommunication of their illness with their GPs during their consultations. This underlying theme is found in these patients' expressions of difficulties in their experiences of 'unhelpful', and 'lengthy consultation', and also found in the actions of those three patients who had said that they 'could not wait longer with the pain' and decided to seek care from the A&E by themselves.

4.3 Delaying diagnosis and treatment: referral systems problems

The study findings confirm previous research in the UK that indicates the patients' pathways to TB diagnosis involve General Practice and hospital A&E services, (6; 7). It is also clear in this pilot the pathways to TB diagnosis involve private hospitals that was not highlighted in the studies reviewed. One interviewee, (pt. 10) reported delay for several months with a severe abdominal pain and

deterioration of health while in her GP care; before he referred her to a local hospital for diagnosis. According to her story, she then had to wait well over a month before she saw hospital physicians. Another patient, (pt.5) who contacted his GP a year ago, had tried herbal medicine and also antibiotics offered to him by his friend, as the treatment offered by his GP did not offer help for his illness. According to his story, he took antibiotics his friend offered him for two days and felt well for seven months. He was then admitted with a severe abdominal pain necessitating a lengthy procedure of TB diagnosis. As Farmer points out, the western health care professionals need to be aware of the patients' perceptions and strategies of health seeking as it differs from their western bio-medical practices, (13).

Previous studies have indicated that delaying diagnosis by patients related to their misinterpretation of TB symptoms. In this pilot, misinterpretation of TB symptoms involved the patients' GPs. From these patients' accounts it was clear that most felt that their GPs were not listening. Even though they had told them; their symptoms were often interpreted as muscular pain or flu and was offered of a pregnancy test to woman with abdominal TB' (pt.1,3,5,8,10) The perspectives of these five patients interviewed highlighted delay in diagnosis associated with GPs not being able to refer to diagnostic services. Previous qualitative study reported delay associated with the general practitioners' care in south east Wales, (9). The preliminary findings of this pilot confirm misinterpretation of TB symptoms, poor regard to patients' concerns, and a lack of follow up, delaying referral and access to TB diagnosis and a lack of coordination of patients' pathways to TB diagnosis.

The study also provides an insight into the referral pathways to chest clinics, particularly the sharing of TB diagnosis test results for ambulatory and hospital inpatients. Some ambulatory patients, (pt. 5, 10) reported diagnosis and start of treatment achieved in hospitals, and also for four patients who were admitted in hospital, (pt. 4; 6; 7 and 8). Whereas for one patient (pt.2) who had been diagnosed with TB by private health care, the test results were sent to the GP to refer her to the chest clinic. As in her accounts, the GP had been reluctant to act on the letter he had received from the private doctor assuming that the private Dr's referral letter would be received and acted upon by the chest clinic. Another male patient, (pt.3) who had a lumpectomy in A&E needed to see his GP in order to be referred to the chest clinic. As he had stated, he only received a phone call from the GP telling him to attend an appointment at the chest clinic and no other information, according to his accounts. The patients' story highlights current knowledge gaps particularly in the post diagnostic phase involving GPs, private health care and A&E and chest clinics. The theme of miscommunication is common to those interviewees who were experiencing referral delays by their GPs before and after diagnosis. A more focused and detailed research with the remaining patients would be needed if we are to learn more about the pre and post diagnostic referral pathways to chest clinics where most patients receive their treatments.

4.4 Lack of sufficient information on TB, diagnosis and treatment effect

Despite many contacts with professionals, some patients' understanding of risk associated with TB and illness appears to be insufficient. One non pulmonary TB patient, (pt.4) interviewee thought he would not have been at risk of TB while visiting his friend who had a pulmonary TB as he was not sharing a meal with him.

Another patient, (pt.5) reported that despite several consultations with professionals, his demand for an explanation as to why the treatment he had taken for 3 and half months was unable to cure his continuing cough problems. The accounts of a patient, (pt.8) born in UK highlighted her lack of knowledge of what was going on when she was admitted in hospital. Although she felt better informed by a student nurse than her doctors, she felt alienated with no information and choice throughout her diagnostic tests. Due to a lack of information, she attempted to search for information on internet as she felt more anxious and worried. However, some were very satisfied by the information they had received from health professionals during their illness - particularly two patients who sought care from private doctors and the six patients who consulted Drs and nurses in A&E and hospital units. However one patient, (pt.8) reported that her experience of hospital staff

involved a complete lack of communication of information throughout her undergoing several diagnostic tests. Consultation with GPs was only perceived as satisfactory by one, (pt.9) of the eight patients who consulted their GPs before and after diagnosis; except two interviewees (pt.1 and 6) who thought they were given information they needed and were listened to after their diagnosis. Whilst the need for information was greater during and after diagnosis the interviewees' accounts of some hospital doctors or consultations, by and large, with their GPs had been inadequate, particularly miscommunication of information at times of their real needs.

4.5   Need for information: pre/post diagnosis effects of TB treatments

The start of treatment for TB was reflected upon by all interviewees beginning with their initial stage of seeking medical help for illness they had experienced. Following their diagnosis, there were mixed feelings about being diagnosed with the disease. Prior to diagnosis most patients who were given treatment by their GPs thought the treatment was repetitive, unhelpful for a lengthy period, without seeing any improvement of either symptoms or pain they had experienced.

Following diagnosis however, after starting TB treatment most patients felt better and only four patients (pt. 4; 5; 7 and 10) complained: headaches, prickling, itching and burning sensation, hair loss, noticing blood in the cough, cramps in the leg and abdominal pain. One interviewee (pt.5) expressed a lack of confidence in the treatment of his cough, despite having a three and half month treatment. Another patient (pt.8) reported how his severe headache, high temperature and increased blood sugar levels that could not be controlled by medication, led to his feelings of poor recovery, as he could not find on explanation for the lack of improvement.

By far the commonest of all interviewees' experiences was getting used to taking a lot of tablets. Most patients reported how they disliked taking tablets in general. However, their understanding of compliance with TB treatment was so strong that almost all of these patients reported the success of their treatment and showed their commitment to completion. The stories of two patients, who have expressed doubts on the success of their treatment of symptoms they were experiencing, highlighted their need for information that could be understood by them. Researchers in Lima documented how the failure of TB treatment to cure illness and adverse reactions to treatment experienced, limited patients' compliance to their treatment, (14). In view of the complexities of factors determining patients' adherence to TB treatment; the stories of these patients are useful for further thought into identifying patients' perspectives with the remaining research subjects more fully.

4.6   Limiting contact with others: work, study and relationships

In addition to their anxiety about their illness, interviewees also described their ongoing worry about the effect their illness has on their career and relationships with others. Three student interviewees, (pt. 1, 8 and 9) reported how their illness experience impacted on their ability to continue studying. They also stated how the students and their tutors provided support for them to continue studying at home. The support from close family members, friends and neighbours as well as relatives abroad has been crucial for them to continue with treatment. Following diagnosis, some of these patients reported that their close contacts needed to undergo a TB test - this has reinforced the decision of five of these patients to limit their contacts, (pt.1, 2, 3, 5, 7) with others. However, most patients reported that they are aware of little risk after two weeks of TB treatment. It was however, unclear as to why the two patients, (pt.2 and 3) with non-infectious form of TB needed to limit their contacts.

Two interviewees (pt.3 & 5) have changed their address during their illness. One patient had stopped his work, (pt.5) and the other (pt. 2) decided to take precautions while still living with her husband and friends. One interviewee, (pt.7) reported how complying with his doctor's advice on limiting his contact with anyone he had known for six months made him, as he described it, a 'prisoner sitting down and counting the day' to restore normality in his life and relationships with others.

Deciding not to disclose their illness to others, particularly to family abroad, was due to the concerns about knowing the anxiety and worry that may be caused to their relatives from accounts of five interviewees, (pt. 1,2,3,4,5). Three patients, (pt.4,7,9) reported the presence of stigma surrounding TB and none of these patients had the experience of stigma either in the family or in the communities where they live. However, a UK-born PTb patient,(pt.8) reported that she was kept in hospital isolation not knowing what was happening, alienation and embarrassment and she described her treatment as being like in quarantine. Two interviewees, (pt.4 and 6) were also admitted to isolation units but they described their need for information as adequately met and did not make any reference to the hospitals' isolation procedures. The east London study, (8) has found stigma associated with health care infection control procedures as it emerged in the experience of a UK born pulmonary TB patient. Amongst the three patients, (pt. 4,7,9) who raised the presence of stigma in the community, one of the patients; (pt.7) had limited contact with his sister and close friends as a means of avoiding rejection by his family and his own community.

The interviewees reported their concerns in relation to them being a risk to others as their main worry they have gone through following their diagnosis. Their reflection on the consequences of continuing their relations as before with those who live close to them was a dilemma central to their thinking that influenced what they thought would tackle problems. A young south Asian patient, (pt. 1) with pulmonary TB described how he told his cousins that he considered going back to his country and was then, told by his cousins to stay and finish his treatment and they cared for him during his illness. From the story of a young UK born pulmonary TB (PTb) patient she felt responsible for her 'close friend who was diagnosed with TB' and had not been informed to limit contact with anyone including her family, (pt. 8). It was apparent that some interviewees, who decided to limit their contact, were on treatments between 3 and 6 months and had pulmonary TB (pt. 5 and 7). The meaning underlying the interviewees' action of limiting contact may relate either to the patients' experiences of being asked by health professionals to give details of people they had contacted - repeatedly mentioned by interviewees, or to their understanding of the little risk while being on treatment. This underlying theme found in the stories illustrates the interviewees' experience of miscommunication with health professionals that were not sufficiently captured to make connections in the data itself. The section that follows will provide part II of this report, it is divided into five sub parts: a summary of pilot research findings, the research question, the methodology and analysis of the main research and also a topic guide for the remaining interviews.

5. Implications for main research

The major experience that is consistent in the interviewees' story relates to the delayed access to diagnosis in London, particularly in the pre-diagnostic care pathways from GP's and also for some hospital ambulatory patients referred from GPs and private Drs. Amongst the constituents of patients' expressions, feelings, and actions in their descriptions of their medical help, the theme 'miscommunication' appears dominant in relation to patients' experiences of health professionals' consultations. This theme was common during interpretations of their illness, when they required information on their illness; at times of need for referral to diagnosis; when seeking to share their concerns, preferences and choices. The theme[15] of 'miscommunication' also featured between health care systems: during processing patients' referral letters, sharing key diagnostic test results for some of the patients.

- Several contacts and misinterpretation of symptoms by their GPs.
- Being on treatments from GPs that had no benefits, i.e., painkillers.

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[15] According to Denzin & Lincoln, themes are abstract (and often fuzzy) constructs found in the texts and also in images, sounds and objects. As constructs they define the expressions and actions of informants. In social science researchers can induce themes from the data or develop them from the background literature. In a careful line by line reading of the text, looking for assumptions, consequences, presence of repetition of words, and looking for metaphors people often use to describe their thoughts and behaviour are ways of identifying themes from the data, (Denzin & Lincoln p.780-81)

- Inappropriate referrals for tests by the GPs unrelated to their expressed illness.
- Long hospital appointments and repeated diagnostic procedures.

The experience of inadequate medical help was also continued following diagnosis to starting treatment in one of the interviewees. The stories of patients interviewed highlighted and the pilot preliminary findings confirm previous research undertaken by Metcalf et al (9) in south East Wales, and identified a new gap in knowledge associated with miscommunication of post diagnostic referral delays by GPs.

5.1   Research Question

The analysis of the pilot findings reveals that one specific theme; that of miscommunication between patients and professionals and also between providers of care has emerged consistently from the accounts of most patients interviewed. The main research will seek to answer the following research question:

> What do South Asian and African TB patients in London say about their experiences of access to TB diagnosis and treatment? More specifically their experiences of miscommunication during medical consultation from the time they first contact health care professionals to TB diagnosis and treatment.

5.2 Methodological Foundations

The research will investigate patients' experience of pathways to TB diagnosis and treatment using patients' stories applying a narrative[16] human science research approach (stories told by research participants – which themselves are interpretive), *(11: p.6)*. Narrative interviewing method is a subset of qualitative inquiry, a new development in social sciences which can be adapted and combined to a range of theories and epistemologies and applies to cross-disciplines boundaries, *(11: p.14-7)* in research. As Riessman points out, the narrative method is not confined to the rules of any one discipline (theory) and also an investigator controlled research practices, *(11: p.15)*. In this method, knowledge is constructed in the everyday world through ordinary communicative act. We can make connections between biography and society through the close analysis of stories,(11) .

The method is particularly useful for this case-centred approach in research where an individual patient is the unit of analysis and the focus is on the content of his/her stories - what he/she says about his/her experiences of medical help. The theme miscommunication has consistently emerged within the context of patients' medical help as the accounts of most patients stories have clearly demonstrated.

5.2.1   Thematic narrative analysis

The pilot study provides an insight into the importance of a non theory driven case-centred approach for understanding of why and how each story developed by the 'narrator' (interviewee) in a particular context of events generates categories of themes. Adapting from Riessman's approach to narrative analysis, - a thematic narrative analysis approach, *(11: p.53-76)* will be used in analysis of data, researcher will follow data analysis: 1. Giving emphasis is on 'the told' – the events and cognitions to which spoken word refers to (the content). 2. Viewing language as a resource rather than a topic of enquiry and themes are unmediated by the researcher's prior theory. 3. Searching for new theoretical insight from the data. 4. Keeping the story intact for interpretive purposes and attend to time and places of narrations and reject the idea of generic explanations. Attending to the

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[16] According to Reissman the term 'narrative' and as a concept carries a number of definitions by different disciplines. A very restrictive definition of social linguistics on one end of the continuum refers to a discrete unit of discourse, an extended answer by a research participant to a single question, topically centred and temporally organized. On the other end of the continuum social history and anthropology, where narrative can refer to an entire life story, woven from threads of interviews, observations and documents, (11: p.5)

context and detail contained in long sequences of stories told. 5. Theorizing from a case rather than from components themes categories across cases

In analysis, the DH strategic framework, (2) for health and social care delivery will also be used to aid the analysis of themes from the data. According to 'Ensuring Better Care for All' the DH Strategic policy framework, (2) each individual's judgement of their experience of medical help and care has a unique basis and depends on many aspects of their care. An individuals' judgement of their care is considered to involve factors such as service: accessibility, timeliness, quality, safety, effectiveness, dignity, respect, meeting expectations, sensitive to personal needs, (2: p.9). Some of these factors are obviously linked to a number of issues discovered in the pilot, and the section below will discuss the significance of the research.

5.3 Description of methodological justifications

The research approach has two main rationales. Firstly, a narrative research method gives emphasis on a case-centred approach to generate detailed accounts of patients' experiences. In so doing, the method provides means to investigate patients' experiences of communication with health care professionals and their experiences of health care systems referral procedures and pathways for them to obtain TB diagnosis and treatment. The findings of this research will provide an empirical basis to contribute to public health practitioners and local policy makers' efforts to TB intervention strategies.

Secondly, on a theoretical level the research approach is useful to extend or fill in gaps in current knowledge about health service related factors associated with the sub-optimal care of TB patients. As Cohen et al assert, health behaviour interventions often put emphasis on patients rather than scrutinizing the health care system's ability to provide high quality, readily accessible services to those most in need. In the case review of a young Haitian man with multi-drug resistant TB, the story depicts how the patient's compliance and family support had mismatched the sub-standard care and uncertainty surrounding the availability of his TB treatment that led to his death, (15). Below is a topic guide that will be used to investigate patients, experiences of medical help and consultations leading to diagnosis and starting TB treatment.

5.4 Interview Guide

The Topic guide will be used to understand patients' experience of pathways to TB diagnosis and treatment. More specifically the questions will attempt to explore chronology of events from first patient contact with HC professionals to diagnosis and treatment – paying attention to his/her experiences of consultations, outcomes. Reasons if patient had sought care other than his GP, an A&E or a private health care etc.

6. Conclusion

Because data gathered in the pilot involved a small sample of patients, it is not likely to have captured the full range of experiences of African and South Asian TB patients. However, in the pilot an attempt was made to account for difference of age, sex, ethnicity and Type of TB in the recruitment of participants led to the recruitment of more subjects in the pilot. The pilot findings illustrate the complexity of end point utilization of TB services health care seeking. Therefore it is logical that the commonalities of most participants' experiences of positive support from family and friends could be due to small numbers involved and differences may exist that are not revealed in this pilot study.

The difficulty surrounding the recruitment of UK born TB patients is a particular learning area for the main field research. During May only two patients had volunteered - the second volunteer who was a UK-born Asian was unable to participate in the interview. In a further contact by a nurse who approached the patient she revealed that her reason for declining participation was personal. It was apparent from the experience of a UK born Africans with pulmonary TB; further research

focused around the emerging theme would also be relevant to a smaller number of UK-born TB cases. In conclusion, the points stated above are main issues arising from the pilot research to be addressed in the remaining research field work. These issues are:

- The remaining interviews will attempt to explore the influences of family and community as part of general questions, (16, p.56).
- The interview questions (see Topic guide) are more focused around patients' experiences of medical consultation, exploring any miscommunication with health professionals as well as also their experiences of pathways to health care systems and providers of care.
- Future research is needed to examine potential differences in access to the NHS primary care that was not explored in this pilot study.
- The recruitment of UK-born subjects will need to be reduced to 6-8 patients.
- As the next part of research will also include non English speaking volunteers, an attempt will be made to obtain support from the NHS providers to cover the cost of translators.

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Appendix – 1

Below is a story of illness experience from a long narrative told by pt. 10 (pseudonym). The patient was accompanied by her husband and two children when attending her treatment at the chest clinic in Newham. The narrative was constructed by the patient and some information also provided by her husband and both speak English. (The abbreviation St in column refers to 'Stanza' meaning the thematic point in the narratives.

	Background	
01	My name is (pt.10) I'm 40 years old I come from Somalia I'm married I live with my husband and our	
02	four children. I live in.... I came to London in 1999 10 years (yehha...confirming with her husband) -	
	First illness experience	
03	It was in October last year I start to feel unwell and my stomach starting to swell.	
04	My stomach got bigger and bigger and periodic fever sometime at night as well I made an	St 1
05	appointment to see GP as well and the decision is myself	
06	I thought I had some gas problem & indigestion	
	miscommunication of illness with GPs	
07	My GP gave me Gaviscon and antibiotics in October last year (confirmed by her husband)	
08	I had temperature and my lung was paining as well, the cough was al ittle bit not much it was a dry	St 2
09	one. But just continue to see the GP and explain about my problem	
10	It took a l lot to discover the illness. The GP checked my stomach	
11	he just suspect of gas and pregnancy as my stomach was big	
12	They gave me antibitics four times, it was four times I remember.	
13	I went first time they gave me antibiotic I used it it did not help me	
14	I went again they gave me antibiotic	
15	I went again they gave me antibiotic it did not help me went again and again for four times it did not	
16	help me	
17	All these time I was telling them the pain the temperature, sweating at night a little bit cough they	
18	continue to give me the antibiotic for the fourth time	
	Referral pathways – delayed TB test	
19	I was referred to hospital in December 31st of December	St 3
20	It was after the fourth time another GP a lady GP who is not a regular GP referred me to hospital	
21	straight away.	
22	In the hospital they start to make appointment for the scan for the stomach, and for the chest	
23	They started the X-ray they take some fluid from my stomach for the first time	
24	Then from the lung as well for the first time	
25	No result at the time the appointment it took too long	
26	and the illness gets worse as the appointment took may be a month or two months	
27	The hospital apppointment was too long that's why it was a problem	
28	They took liquid from my stomach and from my lungs	
29	I think the sample was there the chest phycisian suspected that he said this is sign and it may be TB	
30	He said that, he received information from another doctor I saw several doctors in the hospital.	
	Effect of being diagnosed with TB and family experience	
31	To discover the TB it took a month and half may be it was on 17th of January may be	St 4
32	I was admitted before knowing what the causes of illness was	
33	They were afraid to give me anything and I was admitted in hospital for ten days	
34	They discovered it after four days of admission in hospital	
	Unexpected outcome of TB test and not knowing about TB risk	
35	Knowing it was TB was a shock you know my husband was shocked because it was not small it was	St 5
36	big I did not expect I had TB....it was surprising because we know it is infectious disease it was	
37	surprising to know it was TB. We were surprised that where I got it from ...yehha ...it was surprising	
38	to ourself where I got it from.	
39	I do not know anyone with TB. Because it was infectious disease you must be infected from someone	
	had TB.	
40	**Experience of treatment**	
	I had no problem with the treatment you know and they did explain about the TB and the treatment	St 6

41	options. You know I was happy to know I mean what causes what type of disease it was I have been	
42	here and there without medication and not knowing what it was now I know I can start medication	
43	and start to take medication and start to feel better	
44	My temperature and paining in the lung is gone, before I was losing weight so much. I lost seven	
45	killos. After taking medication about a month start to gain weight. After taking medication the tablets	
46	there was a pain side effects like needle pain on the muscles.	
47	Taking medication in general laughter ...it was not that difficult at all. The only problem is the swelling	
48	on the neck but now I feel I can go everwhere. Before I was feeling weak and now I can go and do	
49	things.	
50	The swelling is still stable you know. I was for four months and one week on treatment. The doctor's	
51	said it will take upto nine months it depends upto one year. Before they told six months and now the	
52	doctor siad to me may	
53	take nine months. It is alraight because I'm sick.	

Feelings about medical help from GP

54	Yehha ..you cannot blame him because this disease sometimes it is too hard to discover by yourown	**St 7**
55	eyes if you take sample you can discover by your eyes yo may think it may know what it is, within	
56	your own eyes it is difficult to say what it is.	
57	For the temperature I used to take pain killers	
58	I think it is the only problem it is not to blame the GP I think except I mean it took so long before	
59	referred to hospital in hospital I was given different appointments every appointment took one or	
60	more than one month in the hospital.	
61	To see my GP was very short time but the appointment in the hospital took long time for the scan and	
62	everything.	

Hospital experience of time taken before treatment

63	The experience...I can say they work hard..I can say it is not bad we thank them it took six weeks to	**St 8**
64	start treatment. The admission was 17th January ...and start treatment on the 20th of January.	

Effect of diagnosis on self, the family

65	Knowing it was TB was a big shock you know sometime you have to accept it can happen to anyone.	**St 9**
66	You must get shock when you get bad news it is a normal thing	
67	Ehhee I don't know what can I say...they did not affect any of of the family.	
68	I did tell those I know I had TB and no problems	
	(Interruption by the nurse children were brought in to stay in the room with their parents)	

TB test experience and treatment involved

69	The hospital the test they took sample it invilved a little bit of pain ...it was painful but when they	**St 10**
70	finish the pain has stopped. They have explained to me what is going to happen and the pain as well.	
71	The tst is a new experience especially taking sample from the lung and the stomach.	
72	In the hospital they explain to me that you can get on the bus train and many people when someone	
73	coughs sneeze... They explain it takes ... six months may be long sometime but they told us it is	
74	curable.	
75	I do not know TB takes many years to develop into illness 'Hooo...it takes upto five years I donot	
76	know that.	

Experience of help from treatment centre

77	I have been coming here (chest clinic) for treatment for more than eight weeks upto two months. The	**St 11**
78	experience is OK coming regularly for treatment is alright with husband and children	
79	It did take long before starting treatment my illness it did get worse ... but thanks for the treatment I	
80	feel better I've been taking treatment for four months, and gaining weight no problems except the	
81	swelling on my neck.	

Feeling about medical help experiences during illness

82	For me the only thing is.... if someone tell you how he is feeling with the swelling of stomach and pain	**St 12**
83	you should make sure it is checked quickly...two months waiting for treatment to start makes the	
84	illness worse and make her feel like pregnant but she is not pregnant. When someone coughing had	
85	a temperature at night and sweat and a big tummy they should have suspected this may be TB.	
86		
87	Before I did not read any leaflet about the big stomach. *(husband)*	
88	My temperature was increasing only at night. I feeel very hot and sweats a lot and I wake up in the	
89	middle of the night. The condition was unbearable and I was surprised myself by the experience.	
90		
91	When I feel hot I take paracetamol ehhe.. I felt fedup of taking tablets because I did not know what	
92	the problem was at the time.	

ANNEX -3

1. Research information data management tools

Participants' selection procedure
Participants' information sheet
Consent form
Narrative interview Aide-Memoire
Interviewee feedback letter
Interviewee transcription quality check form

RECRUITMENT OF VOLUNTEERS FOR THE RESEARCH

Recruitment of volunteers for the research involved treating physicians/nurses informing potential volunteers about the research and giving the contact detail of the researcher for further information about the research. The researcher will be at the clinic site to explain to volunteers about the research and participation in this research is voluntary.

The participant will be selected by their doctors and nurses using the following selection criteria:

Inclusion criteria

- Patient is currently receiving treatment for TB.
- Adults, 18 years of age or older
- South Asian, African ethnic origin
- Able to understand and speak English
- non English speaking volunteers through professional interpreters
- Small number from other ethnic groups
- Born in UK
- Born abroad
- Other volunteers from other ethnic groups

Procedure:

- All subjects will be informed about the research by their doctors and nurses.
- A treating physician provides information to potential volunteers on how to contact the researcher.
- The researcher will be at the clinic site and will arrange a convenient time to explain the research.
- Recruitment of subjects will involve explaining the purpose of the study, answering participants' questions and explaining confidentiality and anonymity issues.
- Once a patient has agreed to participate, patients will be asked if they give consent for their GP to be informed of their participation in the study.
- Volunteers can withdraw at any time.

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Patient Information Sheet

The title of this project:-
An exploration of help-seeking experience of ethnic minority TB patients and
the role of providers of TB services in London

Who is the researcher?
My name is Lemma Yilma I am a male research student at the London School of Hygiene and Tropical Medicine, University of London. I am currently carrying out research with NHS patients to learn from their experiences of NHS services in London. Please take time to read the following information about the research.

Who is organizing and funding the research?
I am carrying out this study to learn about your experience of the NHS and local authorities during your illness, so as to produce a report. I am doing this research independently with the help of lecturers in my university. In order to understand your experiences clearly, I will need to talk to you face-to-face so that I will be able to ask questions and discuss more freely. I am currently based at the university and have obtained financial support from ...... to cover my research costs.

What will the research include?
This research will involve face-to-face interviews with NHS patients, and with professionals: in the NHS, local authorities and health protection units in Newham, Lambeth and Brent. The research will also involve focus group interviews with service providers in these three areas. You will be involved only in the face to face interview. If you agree to participate, I would like to arrange the interview anywhere convenient for you. The interview will take approximately an hour. I would like to record our conversation so that I will be able to ensure that I have correctly understood your experiences.

Why have you been chosen?
The doctors and nurses have been asked to provide information about the research to suitable patients attending the clinic where you are currently receiving treatment. For this research we will require forty patients who have been approached by doctors as suitable for the purpose the study. Your participation is voluntary and you can refuse to take part in this research. However, if you decide to take part in the study, the doctors and nurses in the clinic will give you necessary information on how to contact the researcher. The researcher will be at the clinic site and can arrange a convenient time to speak to you.

The purpose of the interview
The purpose of the interview is to learn from your experience of obtaining medical help, and support you have received at the time of your illness. No other issues or
subjects will be discussed in this interview. Your experience of NHS services will be useful for me to understand the support you have received.

What will happen if you take part?

There will be only a few questions for you to answer directly. **It will take approximately an hour to complete the interview.** It is your story and experience which is important for me to know in order to gather ideas from everyone interviewed and to develop a bigger picture of services for your illness in London. I may take a few notes, but no information I collect from you will contain your personal details: e.g., your name or your address nor any other details describing who you are. I will need to keep a record of our conversation coded anonymously for me to remember my discussion with you. Without your permission, no other person will have access to this information. If necessary I can arrange for the interview to be conducted using an independent and professional interpreter and we will not ask anyone who is known to you to translate in this research. After I have completed the study the audiotape and other paper documents will be stored in the university secured storage for 3 years. It is a normal procedure at my university that all archived data after this period will be destroyed. Should you have any objection about any of the procedures I'm happy to discuss your concerns.

What are the possible advantages of taking part?

This study will give you the opportunity to share your feelings and experiences whether good or bad about the support you have received throughout your illness I hope this will lead to improved services for everyone in London. After I have completed my report I can meet you and others I have interviewed, as a group, to discuss what I included in my report. I will also summarize my report and make it available for you from your GP practice or your neighborhood office.

Who has reviewed the study?

The research plan has been assessed by my university tutors and examiners. The research plan was also assessed by the university ethics committee (London School of Hygiene Tropical Medicine), and the St Mary's Research Ethics Committee (LREC) and it has been finally approved by the....London National Health Service Local Research and Ethics Consortium.

What if you feel distressed or embarrassed by the questionnaire or during the interview?

If you are feeling uncomfortable or feel embarrassed please feel free to discuss this with the researcher and you can stop the interview any time without giving any explanation.

What if you are unhappy about how you have been approached or treated by the researcher?

You can always tell the researcher the issue you are concerned about. If you're still not satisfied, you can raise your concerns to: Mr Andy Sloggett Project Supervisor at the London School of Hygiene and Tropical Medicine on telephone: 020 7299 4628 or write to him at the address: Centre of Population Studies, 50 Bedford Square, London. WC1E 7HT

Contact for further information

If you have any concerns or worries regarding this information, I am available to meet with you and discuss any issues. To discuss issues over the phone please call, **Lemma Yilma** on my mobile on: **07532 278 713**

Thank you very much for your help with this research.
LREC Study number........................
Participant number/cod

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CONSENT FORM FOR INTERVIEW

Participant Identification Number for this study:................................. ....

Title of Project: An exploration of help-seeking experience of ethnic minority TB
patients and the role of provider of TB care services in London

1. I have read and understood the information sheet	Yes ☐	No ☐
2. I believe I understand the purpose of this research and the method of my participation	Yes ☐	No ☐
3. I understand I can stop my participation at anytime and can refuse to answer any question(s) without having to give an explanation.	Yes ☐	No ☐
4. I give permission for information to be used for this research anonymously with no disclosure of my name, address, or my personal details, neither verbally nor in writing in any report from this research.	Yes ☐	No ☐
5. I agree my words may be quoted in a report, in line with conditions stated above.	Yes ☐	No ☐
6. I agree to the transcripts and audiotapes being archived safely	Yes ☐	No ☐
7. I would like to see the copy of my transcript	Yes ☐	No ☐

Participant:
I hereby give my informed and free consent to be participant of the study.

Name	Date	Signature

Researcher:
I agree to conduct this research in accordance with the constraints imposed by this document

Name	Date	Signature

Lemma Yilma _____
Two copies of this page: 1 for participants;   1 for researcher

In-depth Narrative Interview
Aide-Memoire

Opening 'rapport'

Thank you for agreeing to talk to me. As we have not met before, I would like to introduce myself. My name is Lemma Yilma and I am a final year student at the London School of Hygiene and Tropical Medicine. Your doctor or nurse may have explained why I need you to participate in my study. I am interviewing patients in order to learn from their experiences of medical help for their illness. The patients' experience of medical help is the focus of my research in order to write a report as part of my preparation for the degree in public health. The interview is usually takes from 45 minutes up to one hour to complete but it would depend on the amount of information you are willing to share with me. If you are interested in taking part – if so, I shall proceed.

　　　　First I would like you to explain about this research and the information sheet which I would go through with you as well. All information you share with me will be kept in a strict confidential way and you will not need to tell me your name or address or other personal details in this interview. If you do tell me, I'll not use your personal information in the writing of the report and it will be kept confidential and I will not share your personal details with anyone without your permission. I am particularly interested about your first and current experiences of your illness and how have you come about obtaining medical care, if you can remember the dates of your contacts and describing where you have gone during your illness to obtain help. You may have had some good or bad experiences and I'd like to hear them all, as they are important for this research. After I have completed the study all information will be kept safely for few years and will then be destroyed. In order to proceed to the interview, I will need your agreement on this consent form which you will need to indicate your responses by ticking in one of the boxes for each question on the form and signing and date it if you can please.

Step	Contents of narrative Interviews	Tasks
1	First, I would like you to tell me who you are: your background about yourself, your job; where you were born; your origin; and how long you have been living in London and also like to know if you are registered with a GP.	Orientation
2	**Q1. Please tell me about your experience of medical help for your current illness?** If you start how you come to have known about your illness and what you have done about it as you remember them. I am more interested in listening to the story as a whole than asking you questions.) **Prompts** I used appropriate prompts to invite story teller to recollect on events experienced until the narrator signals end of his/her story – CODA. What happen next? Then what? What did you do? What he/she say? What did he/she do? Was it really? I missed what you said then can you please repeat? Can you remember the dates? Where was that (places)?	Main Question *(Inviting)* Story construction: *(listening and attending)*
3	**Model Clarifying questions**: (only asked if missing from the interviewee's stories) Q2. Were you registered with a GP or a family Dr? If not registered with a GP, what did you do to obtain medical help? Q3. Please tell me about what led you first to contact a health care professional? 　　How long after noticing the first signs did you get to see a doctor? 　　Was he a GP?　　　　　　　　　　　A hospital doctor? 　　A private hospital/clinic/health care?　　Any other? Please tell me who...... 　　How long was that? Please can you remember the date? Q4. If you visited any of the above for the illness you've described, had you sought care always from him/her before for any other condition? 　　What happened in your first contact for your current illness? 　　How long the consultation last? 　　How did you feel after the consultation? 　　Did he/she prescribe any medication? What was it? Q5. Did you feel it might be something more serious than what the doctor had said? 　　What prompted that feeling? 　　What did you do about it? Q6. Please tell me what happened next? 　　How many times did you contact him/her before he referred you for the test? 　　When were you told you were going to have test for TB? 　　Who referred you for the test? Q7. When did you have the TB test? Where?　　　How long did it take before you knew the result? 　　What happened after the test?　　　　　　Were you told before the test? 　　Who told you the test result?　　　　　　When were you informed of the result? By whom? 　　How did you feel when going through the test?　What did he/she say? Q8. Were you admitted in hospital? How long?　　What was your medical care by professionals like? Q9. When did you start TB treatment? 　　How long have you been on treatment?　　　How did you find the treatment? 　　Did you notice changes in your illness after taking medications? 　　Were you asked by professionals about your treatment? Q10.　　Please tell me if there is any other point that you have not covered so far 　　　　　　Thank you	Clarifying questions *(checking the time, content and contexts of teller's experiences)*

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Date 24th March 2010

Dear (Name of the participant),

Thank you for taking part in this research project. It has been a very valuable and useful opportunity to meet and talk with you and learn from your story. With this letter you will find two written versions of our interview record. The first is the full written version of our interview and the second is a summarized version.

As I mentioned briefly at our interview, I would like to ask you to check for accuracy of the summarized version of the transcripts. For this, I have enclosed a form for you to indicate the category that you feel appropriately reflects the summary of our interview record. Please feel free to make necessary changes, either by putting a line across with any dates or words that needs changing, or by using the blank page enclosed for any additional information you feel I will need to include.

Please I would be grateful if you complete and sign the form attached and return to me using addressed envelope enclosed. If you would like to talk regarding the above please ring me during day time on my mobile 07837 901 715 or in the evenings and weekends using my home number 020 8852 4135

Once again, I would like to thank you for all your kindness and support. I really appreciate for all your time in taking part in this research and also for agreeing to complete the form enclosed. As I mentioned before, I will summarize the research report and make it available for you.

I look forward to hearing from you soon.

With best regards,

Lemma Yilma
5th Year Candidate
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PARTICIPANT TRANSCRIPTION QUALITY CHECK

Participant Identification Number for this study:.................................. ....

Title of Project: Pathways to diagnosis and treatment: TB patients' experiences in London.

Dear (*Name of participant*),

I would be grateful if you could check the transcripts of the interview I have carried out with you recently. I would appreciate if you could respond to the section below by ticking the box that reflects your opinion of the transcripts and return using enclosed stamped address envelope.

Please tick the section below as appropriate:

I have read the transcripts and agree the texts in the transcripts are in line with what I said

during the interview and the information is correct   ☐

I do not agree the information in the transcripts reflect my statement I made and I have made

necessary changes accordingly.   ☐

I would like to speak to the researcher before approving these transcripts.   ☐

Checked by:

Name   Date   Signature

ANNEX - 4

Research Supplementary Data

Confidential verbatim transcripts (full interview records)
Patient 39 Core Story Experience Portrayals
Letter to participants (research feedback)
Quotes from Participants' Story Types
Interview transcripts & core story portrayal assessment form

Narrative In-depth Interview
(Verbatim transcripts)

Date:	8th Feb 2011	Setting: 3 – chest clinic	Voice recorder	OLYMPUS WS-311M
Patient:	38	Time: 45 minutes	Word length	4,767

I. Please tell me about your backgrouund, family and the work you do…

P. I'm basically Bengali a house wife and mother of three children all boys. I live in …. in this country more or less basically born here I came from an extended big family nine of us here brothers and sisters older and young brothers and sisters we all born in this country and my parents are a British citizen when I was born luckily when they were on holiday. When I was born my parents did not need to have a visa they already live in UK and British so I was very much considered as British citizen.

I. How do you come to have known about your illness with TB?

P. Well I did not know about the TB because no one in our family or by background had TB before, so I was the first one to have TB when I was contarcted it it is not exactly clear…because as I said no one in the background in my family who had TB so ..but ..most ..before I actulaly diagnosed with TB two and half years back I went to Bangladesh with my youngest he was six months older then now he was four yesterday so he was two and have month before I went to Bangladesh .that's where my home country is ..they think basically I might have brought it from there ..they even think they find all the excuses unless I was in contact with someone with TB in this country, which knowingly I do not know off.

I. Please tell me about your experience of medical help for your current illness?

P. Well basically the first it came you know when the normal viruses and cold weather it was a weather where everyone gets a cough and cold and phlegm and this and that basically I was not getting any better after about a month I had coughing and paracetamol you know the normal things not working so I went to the doctor well I did not actually go to the doctors I phoned them and I said so basically this is what is happening I'm not getting better. They prescribed me a course of antibiotic then after one course it did not work I had another course and he siad for some reason you are not getting better and he gave me for chest x-ray and blood test to be done from there they found ..well one of my lung was severely damaged , a lot of infection there so they ruled out it might be pneumonia because for the TB it did not come to the thought did yet obviously because pneumonia is more a less the same symptoms at the begining so what they thought was pneumonia. So the X-ray reasult suggest that I start with the pneumonioa medication which that took another three months because the see they have to gave a three months courses of something. So after I finished my three courses I went for another X-ray and they found out it has not been cleared more or less the same a little bit better but it has not cleared so he gave me another course of pneumonia medication so one course it is not enough so try another ...

I. Was it still prescribed by the GP then?

P. No well the suggestion from the hospital obviously so after the X-ray they said I should go back to the GP get the results obviously the GP said it has not cleared try another month well secondly after that he kept on asking me am I feeling better no I was going to the GP monthly just like to find out …am I getting better … am I no not realy feeling better.. no no really a bit better but not 100% better not totally better better…. Then suddenly I kept I did start to feel worse everytime and I thought to myself well I cannot be going on like this I was a very active mother now I cannot walk to the town centre this and that ..and I cannot be going like that anymore so he did get to the bottom of what is going on so with my depression and everything. He said (he said) I do look I'm getting worse may be having a bit of TB he suggested obviously he cannot confirm anything without but he thought it might be TB. Even though he was treating me for pneumonia but he said he gave me an emergency admission form and I went to our local hospital which is the …one. So I went there obviously they said why I was there beacuse generally I was not feeling good and in the other admission I have been admmitted for pneumonia so they took me in they checked the blood test and in that and everything. And they took basically my history what is happening so far I told them everything and then if that was happening the pneumonia should have settled by now they looked into it and thjey suspected the same thing it mioght be TB. And then out of no where you know they all started to wearing masks an all this things . I was admitted for two three days. I started to bring sputum then so they actually checked my sputum sample and confirmed it is TB …It was a day lafter it was confirmed because obvsiouslly they cannot confirm after the test of sputum and that they said they cannot confirm it from the sputum but it might not be infectious and even like that. So might have to do a long procedure you know, but the sputum itself confirmed it, so they gave me TB medication and discharged me the following day ..it was on the third day I think

I. What happened then?

P. Well for about six months…it is just like the clinic here in the …chest clinic there I was under different consultant the chest clinic consultant there and I was taking TB medication it is just like here (S31clinic) I was on monthly or six weekly and he was asking me how I was feeling generally and this and that and basically I was saying there was no improvement

I. Did you see any improvement then after the GP's treatment?

P. He said am I bringing up still, I say yes and I was feeling chest pain you know because I was coughing a lot basically there was not anything I was not   seeing anything positive

I. So what happened then?

P.So what happened …(laughter)…it was a long way because I've been this TB is going on for about two years now…so ok the first time I went to clinic they gave me medication they tested all the medication whether working or not and one of them it did not work ...this is the one the first line medication one of them I forgot the name exactly but they said it did not work. They had to swap this medication down these things so they gave me the different ones it was a long process at the end of it medication to work it takes a long time. So all

this things it did not work and in the X-ray they realized that my left lung was severely damaged so they did not think it will repair itself beacause the shadowing of the lung all wiped out they hardly see the lung, in the right side there was a little bit of infection on the right side obviously once I'm better it will repair itself that is repairing itself mostly.

I. **So how were you transferred to X clinic then?**
P. So well...then they realized ...he had a word with one of the S31 consultant for operation and things like that...the clinic in x hospital so week and like that I don't work with them because they donot get operation on me they do want to get rid of the left lung because that scarring and lots of infection so it did not get better. So that is the only way to get me better at the time ...so...anyway the end of June something like that the operation is going to be done they planned it alll out in letter and everything like that was meant to be done at the ... hospital .... (pause -*someone knocked on the door and entered into the room*). So June came along and I was not informed going or anything like that so at the end of June so I say June is gone July is alomost here (loughter), what is happening I was plannig to have the operation at the begining of June so what is happening. .(after this)... I realized that I'm still TB positive something like that, they cannot give the operation and for some how Dr X few days he phoned me up to say I had to go to hospital as an emergency they have got an Isolation room they treat me with you know with injections and all these differenet forms of ?... so that's why the day he phoned me I was admitted that day and he said it is not going to be at Guy's it is going to be at S32 hospital and that was..when it is now July last year (2009)..

I. **Was it in July last year? What happened then?**
P. So I ... well eventually I thought I might be here for two weeks or so and I ended up staying here three and half months. Well then again the new treatment what they came up with it was all they add...extra multi drug resistant TB medications and they had you know that they had injections the drip one which I forgot the name anyway. They had stronger medications basically they gave me extra medications like to get me better and all these they did work so that's why the medications started working we also seen signs of improvement by admitting me here you know. from the medications we could see you know from the medications from a month on the line we could see improvement ...So basically since then I'm not going down slightest ups. it was obviously a slow process because I've been its ehhe been a long time

I. **What did they do to say that it has been improving?**
P. So I'm not infectious anymore so luckily that why I'm not wearing the masks (laughter) so that's why I was not in isolation once I was not infectious anymore three month ...three months and a half later that's why they were able to discharge me basically ..so for about three months I was in the Isolation Room.

I. **How do you feel now then?**
P. I feel very much stronger but still walking outside the cold air and all that it is harder for me to tolerate than the normal person I would say I am not like the person I used to be like before but now I'm not covering my face somethinkg like that I get a lot of cold weather windy thing going in and I cough more so inside (home) i'm fine I'm not coughing anymore but outside the cold air. It does still affect me because obviously still I'm not 100% yet and I'm on a two year course of medications I just got three to seven months only.

I. **Going back from the first time you contacted the GP can you remember the date or the month you first saw the GP?**
P. Ehe... ehe (laughter) ...that's was a long one actually ...I think it is in 2008 in May ...I think it was in May 2008.

I. **When you saw the GP were you taking paracetamol to start with for how long was that**
P. Before for about a month and a month and half then it did not work and I said I should go to the GP

I. **Can you remeber the dates?**
P.No no no the first time I went to the hospital it was May or June ...you know. Me feeling unwell probably be earlier when I was coughing first obviously I thought it was a virus and It was and obviously knowing me I donot like to take paracetamol more thinking let my normal immune system work the majic so probabaly I did get abit weak and then TB kicked in and everything more slightly.

I. **So when did you see the GP then?**
P. So I'll say to be on safe side I"I say I started to become unwell about in April early April the symptom basically like you know it is like fever the normal paerson has a fever, high tempratures coughing, runny nose sometime sweating in the middle of the night. I took paracetamol at home and I've got paracetamol in the cupbord the things like that I did not come to the GP ..I did not come to the GP probably a month later probably is my fault I should have gone to the GP earlier but.

I. **So the GP gave you the first antibiotics and it did not work you went back again... what happens after that?**
P. I did not go in I phoned them because I was not feeling too good I actually phoned and saying these are my symptoms I'm not I had paracetamol all that my temperatures did not seem to be going when I took the pracetamol a couple of hours later my temperature goes back up again. So that's why you realize that paracetamol is not cure you you probably some antibiotic something like that

I. **After that you said the X-ray was done when was exactly you had the X-ray then?**
P. Ehe...(long laughter)...that's I think in May that's when I said I was diagnosed in May they were saying I had pneumonia ...that was the first time when I had my first X-ray. After I had the X-ray two days later usually you have to go in a week to get the X-ray results the doctor phoned me back at home because obviously he has realized on the X-ray it was not normal I got the infection and all that. He said could you please come in quick today because I got so much to talk to you about so I went in that's why he said I have got suspected pneumonia so he said I have to take care and advice and that and the antibiotics

I. **What happen then when the pneumonia medication was not working?**
P. The dates are really difficult obviously it has not been happening in the last year because my first symptom was in 2008 so now it is 2010 it was two years ago so for me to recall exact date is really difficult so if you check my records you will be able to get the accurate dates.

I.**Unfortunately in this research I do not intend to ask doctors or see your clinical records. I'd be interested in getting as much information I can from you.**

I. **When did you start the TB treatment?**
P. The first time ...you know when I said I went to the hospital the first time with the mergency referral it was about a day later ...two days later ...the medication was for a year I did not complete it I had about four or five months left before I was admitted at S32 hospital ..so I went at least half of my course of mnedication I think I did about six months of treatment six seven monmths out of the twelve months course

I. **What was like your experience of professionals' doctors and nurses?**
P. Well I think from the GP's point of view me and the GP probably lucking probably if I was a bit persistent we would have gone in sooner. I don't know but I'm quiet a tolerent person bare things thinking why I should hassle someone when I don't need to type of thinking.

I. **So you were not pushing hard to obtain a second medical opinion is that right?**
P. Yehhaa...I did not do anything like that I just relied with the GP and you know like I just took it

I. **How did you feel about the GP then?**
P. I think what to tell you the truth because obviously we have not got a TB background so he never thought it could be TB I never thought it could be TB. Now obviously I have suffered from TB if I see my children cough and cold and temperature I always think twice now because obviously I know what to think. Even with the normal infection sometime these infections signs are the same as TB infection so I'm aware of it because obviously we did not have TB in the family we do not know what to look out for even the symptoms I was feeling I did not even know it was a TB symptoms it just like a normal cough and cold with high temperature fever I was not bringing up with the cough at the begining no

I. **What was like your experiences of doctors and nurses in hospital?**
P. Oh! the nurses ...they were happy with me, because I was a quite tolerent patient I was not being rude obviously if you are polite to some one they polite back if you're shouting they need to be a bit stubborn obviously me the patient the doctors and staff we did get along.

I. **Being in isolation may be unique experience for you, can you tell me your experiences of it?**
P. Well isolation wise at first I thought I was (masked) in I did not like it was new I did not know what the isolation when my family and everyone had to wear aprons in so for me I didnot really like it because it gives a different picture to someone that side they just scared why I have to do this why I have to do that and they find out I'm infecttious not my husband or anyone but visitors who came to see me like obviously they did not know the full history so sometimes you could see in their face you know so I thought I could see in their face a bit more cautious (fire drill went off in the background).

I. **What about your husband and close family?**
P. My husband ...my children them obviously they did not understand it they thought it was fun words like that. My children at first they have to waer masks at first and then they said the children they cannot go even in the room obviously if they wearing the masks it does not fit them in properly. There is no point in wearing them but they still breathin and everything so they were not allowed in the room only adults were allowed, no children my children or anybodys children. I could not see my children at all basically that was a bit depressing at first and obviously they realize I am going to be here for a long time it is not fare to cut them off the mother and the children bonding things like that. Because it was in july and it was hot and summer day they have their meeting of their own, so I could go and meet them outside in the fresh air. Then again we were not too close they were seeing me and I get to see them play about so I was allowed to see them outside.

I. **Did they explein to you why they have to do that?**
P. Yes...yehhaa...yehhaaa the only thing I would have been happy obviously they did not tell me I'm going to be here

I. **Where did you think you may have been at risk then?**
P. From taliking to mny GP from my families point of view and from my husband point of view who ever I met I don't know anyone who had TB so even the GP said it could even be in the plane you never know because from the plane from Bangldesh to England is in a row you sit there its about eleven hours flight. Eleven hours flight even you contarct TB even you know someone coughing on you for eight hours so easily have been there longer its is quiet small place isn't it? so it could even be in the plane you don't even know the day you were coming back.

I. **What was like for you such long periods of treatment?**
P: It is to tell you the truth when I still think about it it still saddens me I feel with all my treatments and this and that even now when I'm taking my medication I do not feel 100% I feel better when I'm lying doiwn when I'm not thinking about anything that's how I could tolerate it even TB medication is very hard to tolerate you know. Sometimes it makes you cough more like you clear the chest and that. When I cough too much, it makes me sick at the time. even now I am not feeling too good. If I talk a lot my throats get dry I feel sickly sometimes obviously now I'm not feeling so bad you are able to tell from my face.

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I. **What else more than the cough and sickly feelings?**
P. The other experiences just like children love I've not been able to give them more attention I was weak even now they come nad ask me questions and I say please let me have rest the sort of things. They want to know they want help with their homework which I cannot do so most of the time I'm dissapointed with myself for not been able to help my children and my family. Even now my husband having to do all the cooking and the cleaning which I used to do first thing since I've been married. I've been married for about sixteen years now. For the last about two years I've not been able to do any proper house work cleaning wich is not my routine work because I stopped everything so my hasband having to do it so I also feel the weak side depressed side for having and letting my husband do that. He himself is not a well man he has diabetic and he is Insulin depebdent so it is hard to see him do all that when he is not well himself.

I. **How were you able to cope with treatment and care of the children?**
P. No ...not really ...because obviously at the end of it I could still move about and I do not need personal care assistant I could do still do all these things for myself. Usually with TB you get this and help things I do not need those things enenthough I feel tired most of the time but that nothing I can still do. Not offered support even when I was in hospital. The only thing is even now every month having to come every month for treatment here from Knet it is quiet difficult.

I. **What is like medical help through out your journey of getting the treatment?**
P. I started first medication I was taking one of the medication is called Pyrazinamide and that gives me lots of aches and pain and thinhgs like that when I first took it I could not walk at all, I was shuffling here and there like that. So I actually applied for diasability living mobility allowance I have actually got that

I. **Did they change the medication for you?**
P. No I had to stick to that medication because that was the importanbt one I had to take but obviously as time went slowly I started to getting used to it bit by bit with the medication side effect.

I. **Was it part of the extra strong medication you had in July?**
P. No no that one actually ...it continued even though I took it for six to seven months with the new courses of medication they included that as apart of it

I. **How did you feel then?**
P. Well that doctor who came in earlier Dr x and Dr Y they all see me when I came first unwell ...everytime they see me they said you looking well you are glowing these are positive comments and they look at me and see all these obviously I must be feeling much better ...Dr X Dr Y Dr X they all treat me. When I was in hospital Dr Y has not she just seen me once and Dr X one of my main consulatnt. I feel much better now I am happier now obviously I'm still coughing up and this and that I just feel by seven months I should have stopped coughing but I'm doing a littlle bit

I. **Did they explain to you how you're reacting to cold air?**
P. Yes...yes because there is a cold air with the damaged lung and infected lung all that it does affect that type of people more The operation they did say that once my TB is all completely cured after two years course then they will see how I'm tolerating with other infectious diseases you know like cold and that if I'm tolerating the normal person would not need to do an operation but if they see me more weaker and more vulnerable they might still consider that the operation they were talking about. My left lung is is so damaged and it moved to a side ..so eventhough the TB is I'm not infectious anymore my right is cleared there is not much difference in the left lung. They donot think it repair itself unles a miracle happens byt they do not think that it is going to repair itself. So it is damaged. Eventhough I am not infectioous anymore it cannot repair itself. Basically I live on one lung now, by the time they found out my TB it was so badly damaged. Because it took six seven mnths before I started TB medications, it took two three months on pneumonia medication before the re X-ray me so they have to give time to work and clear everything they cannot X-ray two weeks or a month later. I think this is what causes my lung to damage, because obviously if we all suspect it was TB from the begining then I would have been able to start treatment earlier and I think may be it may even have been multi-drug resistant TB obviously if it was minor TB at the time the normal medication would have worked. I think why it is gone multi- drug resistant, because, so it becomes so infectious for the normal medication the normal TB medication did not work, so I needed the stronger medication. Because they said why it became multi-drug resistant because I do not know, because from my point of view, I took my nedication regularly and they usually say people who missing the doses don't take it regularly that's why it becomes multiple resistant, but from my point of view beacuse I want to get better I took all the time and everything like that ....they are based 100% what I know then.

I. **How do you feel now?**
P. How do I feel now ...well, I feel much better being able to be infectious free is one big thing...I know now, I could mix with people without you know when at the back of my mind even when I was infectious I did not want to be close to people. I did not want to put anyone the way I've been through you know what I mean.

I. **Is there is anything else I've not asked you and you may think important for me to know?**
P. No not really.

Thank you very much for your cooperation.

Background *…why they let me suffer … you see how much I suffer from all these… … (Sufferer)*

I am from Iraq, I was born in Basra 1st of July in 1950 I have two children in 1980s. The war started between Iraq and Iran then I came to Sweden and then moved to Britain I have been here (in the UK) for thirty years.

Triggers to seek medical help **Plot 1**
I am severe asthmatic this makes me very very sad and that affected my health especially the weather changes. I started to cough in November 2008 cough, cough, vomiting, cough, vomiting I never ever stopped I can not sleep, I lost about twenty KGs.

First medical encounter medical help **Plot 2**
I went to my GP and I told my GP. He gave me cortisone antibiotics and syrup. I said to him, 'it does not work please do something'. I cannot sleep, I lost about twenty KGs. I told him 'there is something in my simple knowledge the cough is different from an ordinary cough. It became like gray and it's like a ball'. I told him 'I am very hot, please do something please do something and I cried all the time'. He just gave me cortisone antibiotic syrup for many months you know. I put pressure on my GP do something don't treat me do something, I know when GPs sent a patient to the hospital they lose money that's the main important things for him it is not my health its his money that is important for him. So I told him I do not leave the surgery now before he sent me to the Hospital. He said he will refer me to the S11 hospital. After that I did not receive anything from my GP so I went as emergency to the S11 hospital A&E in May 2009. The doctor treated me very very badly. He said, 'there is nothing found in the X-ray and you wasting my time'. I told him, 'there is nothing wrong if I cough for six months and I came as emergency and am an old woman severe asthmatic it is not wrong to come to see the doctor'. He was speaking to me in front of all patients, they hear all what he said, no confediality or nothing so I cried but he was very very tough.

Referral pathways for further medical help and tests **Plot 3**
After that I came home, I received another appointment from the S11 hospital. I saw another doctor in chest department. When he saw me the first time, I explained to him my situation. He never ever listened to me and he said 'it's the vomiting may be something the problem in your stomach or something like that'. He gave me capsule and that is my treatment. He never ever listened to what I said he also treated me very very badly. After an hour long sitting and waiting for my appointment, he told me, 'there is something in my stomach' - he never investigated anything no blood test no no X-ray nothing. An old woman like me I'm sixty this year. I am only grateful to another consultant here (chest clinic), who did the investigation. That was when I received a second appointment I saw a chest consultant (chest clinic). I begged him, I kissed his neck, his knees I swear … (crying). He ws the only person who did the investigation for me, because I cried to him, 'please doctor there is something, I feel there is something I think I am changed' and I'm not the person who I was'. So he did do a Scan and sputum tests as well. He told me, 'to take three bottles and bring it to him the next day and he said I should keep it in the refrigerator'. He saw me, 'I was sweating I was so hot', I told him; 'I cried all the time from my GP to here (to chest clinic). But I can not say anything, 'I am a Muslim woman, I respect my God and I have respect to other people, I let my God punish them' [professionals she saw in earlier contacts]. I also saw another doctor I had the third appointment at the S1 Hospital. So this doctor I saw, she told me, 'at least there is nothing now but she told me the sputum test takes a long time'. After four may be less than four weeks I received another letter from this centre (chest clinic).

Undergoing TB diagnosis and experiences of medical help **Plot 4**
I knew there was something, because the address from the letter was changed from the hospital to this centre (chest clinic). I came here (chest clinic) there was a lady doctor said, 'she doubt I had TB' and I was given another an appointment you see how <u>much I suffer from</u> all these. Then the next appointment they said, 'sorry that, I have TB' - I was 'shocked (paused and crying)', I said, 'why you let me to reach to this point from the begining I needed just the sputum it is very easy - the way as an old lady I coughed all the time, losing weight about twenty KGs. It was very simple anybody can understand this (crying)'. It felt like, somthing hit me by a stone on my head, I was shaking. I only thought it may be something in my lung, may be water. I did not think it was TB.. no.. not at all. So, I cried I said, 'why for one year and two or three months long', for all this time I had no sleep at all and I suffered a lot with flu one after another.

Medical help experiences after TB diagnosis **Plot 5**
I started the TB treatment two months ago (in November 2009). I was feeling sick and vomiting all the time with all treatment they have given me. I do not know why they let me reach this point I told my children and my husband I am not as I am I am changed there is something happenining in my life (crying) it's too much for me to take. I am not a healthy person, I do not need another illness. They could have investigated and treated me earlier. I told the consultant all that. He said, 'he wanted me to see I don't know called a specialist doctor (gastroenterologist)'. I told him, 'my GP will never ever help me, if he would like to help me he should call him (GP) now and I gave him the GP's number'. They (the doctors) said, 'they are worried I may have a TB that is resistant to TB treatment'. May be I did not know, 'it may take one year if it does not cure my TB by six months'. Every two months they give me these tablets but I'm vomiting now every time.

Medical help and treatment care experience **Plot 6**
Since I came here (chest clinic) I lost two or three killos every month I take too many tablets its six tablets vitamins and seven tablets the whole so my body my immune system is very very weak I am becoming worse in all these you know my situation is very very bad. The consultant has called my GP today and he told him to refer me to the gastro medicine. He told him that, 'I had problem in my stomach' and he told him (the GP) 'he can not sit and see me suffering'. I told him, 'if he do not tell him and he would not refer me' and I also asked him to send me copy of his letter so I will take that if the GP said he did not receive any letter.

The ending of the story line: feeling and thinking **Plot 7**
I told you, I started to cough in Novemeber 2008 so the diagnosis was made in a year so he (the GP) let me down. My daughter has said, 'she will go to see my GP and tell him what happened and let him know that he did treat me so badly'.
Feeling now: Closure – coda
I feel with the TB I am still sweating, am very weak, I had no sleep, can not sleep, sweating at night and changing my clothes every time am losing weight, I have no apeatitite for food. I'm taking too much tablets I know I must eat and do something. I'm daily arguing with my family. I did not feel any benefit from the TB tablets and the cough is still going on. On the 5th of March by then it will be four months and the I will start another two months treatment.

Quotes from Participants' Story Types

Plot Types	What do patients say about their pathways to diagnosis?
Sufferer	*I went back to GP, was in agony, could not walk, running hot and cold, (pt.11)*
Doubter	*I kept going to the GP I coughed a lot, cannot breath, or sleep at night. He said it was gave me inhaler when I used inhaler I cannot wake up I could not walk I had to sleep I told him this is not my medicine...next time I got ill I went to the A&E, (pt.12)*
Coercer	*I feel dizzy if I do anything at all I feel tired all the time I feel like sleeping always, I had to fight with them two or three times(pt.13)*
Coercer	*I thought I was going to die but now I think I got new life....they gave me new life, (pt.14)*
Accepter	*I only had a little discomfort on the site, and the specialist and the GPs they actually very supportive, (pt.15)*
Accepter	*I am a little bit lucky I never had all symptoms straight away to the medication I donot feel that illness.(pt.16)*
Sufferer	*it was really hard get hold of the GP and on the things. I was not getting anywhere with it, so I was getting worse again so I went to CAB (pt.17)*
Tolerant	*I was a bit upset of the delay in the A&E at the begining if they started treating me first I would have not been in this position, (pt.18).*
Accepter	*I was so scared of people not about myself or my illness, but everyone was good to me, (p19)*
Doubter	*As an individual you can only take every thing at certain level you can only do as much as you can do. Now I get back and say thanks God I am still alive (pt.20)*
Sufferer	*I suffered so much from April to June only tests and referral letter they cannot treat me I feel so angry. (pt.21)*
Doubter	*I felt that one time they only checking the medicine for me. I worry about developing cancer worry about the effect of TB treatment ... I'm dying not only physically even psychologically, (pt.22)*
Coercer	*I needed to talk otherwise no chance of referral by my GP. If I did not put pressure I'd be the one with the problem not them, (pt.23)*
Sufferer	*I used to go to GP every day as an emergency you know I was quite ill I was suffering a lot and what the GP used to say is go for Ultrasound ...I was waiting ....waiting ...too long, (pt.24)*
Accepter	*If it wasn't for the staff in the NHS I would not have been here and talking to you either. (p25)*
Coercer	*I knew what I wanted was not going to be done by the GP if I listened to him and thought I did not have TB I may not have gone for an X-ray you know.(pt.26)*
Coercer	*I told him I need an X-ray he said I could go when its only a problem, I just made appointment with chest clinic by myself, (pt.27)*
Sufferer	*I was a happy go lucky I never had any leave from work. After referred to ENT I was so ill I could not wait any longer I just went to the A&E and collapsed in the waiting area, that was my very very bad experience, (pt.28)*
Accepter	*I went to the GP and I gave my urine and he checked and he told me my sugar was too high so he told me to go to middlesex hospital and the blood done and also have the X-ray.(pt.29)*
Tolerant	*they did not take me seriously ...they just thought I'm pregnant and doing too much, not a big deal so I'd say I was ignored not given the tests ...I'm a strong person but nearly breaking down, (pt.30)*
Sufferer	*coughing almost for eight weeks taken all antibiotics GP didn't know what was wrong with me he said he has got no choice to refer me for a test probably TB just mentioned it, (pt. 31)*
Sufferer	*I was waiting too long for referral to see the orthopaedist they did not give me any treatment and they did not say exactly what, I went back home (Tanzania) as soon as I got there I just collapsed, (pt.32)*
Sufferer	*my own GP he checked me and said my chest was clear when I saw the emergency Dr he said my chest was clear...the Walking centre Dr said my chest is clear so they cannot find anything, (p33)*
Doubter	*GP said it might be TB ...I said I cannot accept it there was nothing wrong with me I don't drink; smoke and ... my background is always so strong and clear I donot have any disease I've faught it by myself untill now. (pt.34)*
Sufferer	*I was so ill, I went to the GP they gave me appointment for a week that time I came back and I was sitting in the bus stop, collapsed somebody called ambulance for me and I was taken to the hospital, (p35).*
Tolerant	*next time I ...I'll not keep quiet like I kept quiet when I saw my GP I'll air out my views...I rather not keep quiet, talk it out because if you keep quiet you end up suffering (pt.36)*
Sufferer	*I keep telling them the pain is not normal...the thing is that they know that something is not right. (p37)*
Tolerant	*If I was a bit persistent I would have been referred sooner I'm a quiet tolerent person, bare things thinking why should I hassle someone...I just relied on the GP and you know like I just took it (pt.38)*
Sufferer	*I do not know why they let me reach this point, I'm not who I was, I'm changed! There is something happening in my life, (crying) it's too much for me. (pt.39)*
Coercer	*I told my GP if you do not refer me, I'll go as an emergency. He saw me very ill. He then referred me to the specialist, (pt.40)*
Accepter	*I went to the GP and he referred me to the chest clinic straight away. Everything is alright and no problems. (pt.41)*

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ANNEX - 5

1. Literature Review Audit Trails

Table 1. Search Terms
Table 2. Search Process and Study Selection:
excluded, included and reasons
Table 3a UK Literature Excluded at Title or Abstract Review
Table 3b Literature Excluded at Full-Text Review

2. Narrative Review of Literature

Data Synthesis – Narrative Review   (in Portrait)
Table 1 non-OECD Literature
Table 2 OECD Literature
Table 3 Data extraction sheet - (in Landscape)

Table 1 Search Terms. (Medline/Embase search filters adapted from Khan et al. 2001: Literature Searching (see Appendix 1, A1.1-6)

Medline	Embase	PubMed
1. patients/ 2. help-seeking/ 3. healthcare seeking/ 4. mycobacterium tuberculosis.tw. 5. diagnosis delay/ 6. treatment delay.tw 7. treatment delays.mp. 8. (patients adj3 screenS).tw. 9. or/1-8 10. tuberculosis 11. mycobacterium tuberculosis.tw. 12. (tuberculosisS adj2 (diagnosisS or treatment? or testing? or detection? Or assessments.tw. 13. (diagnosis adj2 (tuberculosisS or therapy)).tw. 14. or/1-8 15. or/10-13 16. 9 and 14 17. 15 and 16 18. diagnosis delay.tw. 19. tuberculosis diagnosis.tw. 20. tuberculosis treatment.tw. 21. treatment delay.tw. 22. or/18-21 22. 17 and 22	1 exp 'experience and diagnosis' /or suspects.mp.or'exp Tuberculosis and diagnosis'/ 2. tuberculosis patients.mp.or exp 'Diagnosis and Treatment'/ 3. tuberculosis patients.tw. 4. tuberculosis diagnsosis.tw. 5. (tuberculosisS adj3 diagnosisS).tw. 6. or/1-6 7. and/1-6 8. or/1-9 9. 1and 9 10. exp tuberculosisS/ 11. exp diagnosisS/ 12. exp TreatmentS/ 13. Diagnosis S.mp.or expTuberculosis, Treatment/ 14. Tuberculosis S.mp.or exp Diagnosis, Treatment 15. Or/14-18 16. 14 and 18 17. 13 and 19 18. Exp help seeking, healthcare seeking/ or medical assistance.mp. 19. Exp tuberculosis, help seeking, healthcare seeking/ or medical assistance.mp. 20. Treatment delay.tw. 21. Diagnosis delay.tw 22. Or/22-26 23. 21-27	1. tuberculosis 2. help-seeking 3. diagnostic delay 4 treatment delay 5. #2 or #3 or #5 or #5 6 tuberculosis diagnosis 7. tuberculosis detection 8. pulmonary tuberculosis 9. diagnosis experience 10. patients experience and tuberculosis 11. #7 or #8 or #9 or #10 or #11 12. #5 and #6 13. #6 and #12 14. patients experience 15. diagnosis by primary care 16. tuberculosis healthcare 17. tuberculosis detection 18. #14 Or #15 or #16 or #17 or #18
Cochrane		
1. Tuberculosis 2. Diagnostic delay		

Table 2. Search Process and Study Selection: excluded, included and reasons

Databases	Total searched	Title reviewed and excluded	Abstracts reviewed	Full-Text Articles reviewed	Included for review
Medline	520	512	8	7	
Embase	90	80	10	7	
Cochrane	195	195	0	0	89 – 22 = 67
PubMed	225	163	62	56	
Expanded search				16	
Recommended by others				3	
Studies		Excluded			Included
Total	1030	950	10	22	67
Reasons for exclusion and inclusion		Title does not relate to patients' access to TB diagnosis and treatment.	Lack of focus on patients' TB care seeking. 2 Full- texts non-English.(see p.279)	Remote settings. Focus on staff perspectives. Focus on perception about TB. Research outcomes not focused. Not about help seeking. Focused on risk factors. (see Table 3b for more detail)	Met purpose of review; assessed barriers linked to either patient or provider and involved TB patients.

Table 3a UK Literature Excluded at Abstract Review

Authors	Study Title	Reasons
Callister JEM. et al. 2002	Pulmonary tuberculosis among political asylum seekers screened at Heathrow Airport, London, 1995 – 1999.	Focus on active case findings
Walshman J, & Bashford A. (2006)	Compulsion, Localism and Pragmatism: the Micro- Politics of Tuberculosis Screening in the UK, 1950 -1965 Social History of Medicine 2006 19, 2 page 295-312	TB screening policy
Llewellyn M. et al. (2000)	Tuberculosis diagnosed during pregnancy: a prospective study from London. Thorax 55:2 129-32	Not focused on help-seeking for TB
Mangtani P. et al. (1995)	Socioeconomic deprivation and notification rates for tuberculosis in London during 1982-91. BMJ 310: 963-966	Focus on TB incidence
Rose A. et al. (2001).	Tuberculosis at the end of the 20th century in England and Wales: results of a national survey in 1998. Thorax 56: 173-179	Focus on TB incidence
D Antoine, H et al. (2006)	Epidemiology and response to the growing problem of tuberculosis in London. Surveillance report. Euro surveillance Volume 11 / Issue 3	Not met purpose of review
Welshman J. (2006)	Compulsion, Localism, and Pragmatism: The Micro-Politics of Tuberculosis Screening in the United Kingdom, 1950-1965 Social History of Medicine Vol. 19, No 2 pp. 2295-312	Not met purpose of review
Hogan H. et al. (2005)	Screening of new entrants for tuberculosis: responses to port notifications. Journal of Public Health Vol 27, No. 2, pp. 192-195.	Port entry screening
Brewlin P et al. (2006)	Is screening for tuberculosis acceptable to immigrants? A qualitative study. Journal of Public Health Volume 28, number 3 pp 253-260	It is about screening
Millership S. et al. (2005)	Identification of tuberculosis cases by port health screening in Essex 1997-2003. Journal of Public Health	Focus on active case findings
Underwood, BR. et al. (2003)	Contact tracing and population screening for tuberculosis – who should be assessed? Journal of Public Health Medicine. DOI: 10.1093/pubmed/fdg012	Focus on active case findings
Ruddy, MC. et al. (2004)	Outbreak of Isoniazid resistant Tuberculosis in London. Thorax 2004;59;279-285	Not related to review purpose

Table 3b Literature Excluded at Full-Text Review

	Authors	Study Title	Reasons
1	Needham DM et al. 1998	Barriers to TB control in urban Zambia: the economic impact and burden on patients prior to diagnosis. Int J Tuberc Lung Dis (2(10):811-817	Focus on economic burden. Included another article from same authors & study
2	Mangesho PE et al 2007	Community knowledge, attitudes and practices towards tuberculosis and its treatment in Mpwapwa district Tanzan Health Res Bull. Jan; 9(1):38-43	Not assessed factors linked to patients' care access
3	Madebo T & Lindtjørn B (1999)	Delay in treatment of pulmonary tuberculosis. An analysis of symptom duration among Ethiopian patients. Medscape General Medicine 1999 [http://www.medscape.com/viewarticle/407989]	Focus on symptom duration not on factors diagnosis access by patients
4	Rubel A J and Garro LC. (1992).	Social and Cultural factors in the Successful Control of Tuberculosis. Public Health Reports. Department of Family Medicine. Nov. – Dec. Vol. 107, No. 626-36	Not assessed patients' perspectives
5	Wares DF, Akhtar M, Singh S. (2001).	DOT for patients with limited access to health care facilities in a hill District of eastern Nepal. International Journal of Tuberculosis and Lung Disease, 2001,5(8): pp. 732–40.	Settings with limited access to healthcare facilities
6	Yaya Kasse et al 2006	Aim to understand health seeking experiences of individuals with cough (suspects) BMC Public Health, 6:43 http:www.biomedcentral.com/1471-2458/6/143	Focus on TB suspects and healthcare seeking
7	San Sebastian M, & Bothamley GH. (2000)	Tuberculosis preventive therapy: perspective from a multi-ethnic community. Respiratory Medicine, 94, 648-653	Focused on ethnic group perspectives of prophylaxis for TB
8	Watkins RE, Rouse CR & Plant AJ. (2004)	Tuberculosis treatment delivery in Bali: a qualitative study of clinic staff perceptions. Int J Tuberc Lung Dis 8(2):218-225 (IUATLD) http://qhr.sagepub.com/content/14/5/691	Focus on perspectives of professionals. Included another from same authors & study
9	Somma et al. 2008	Semi-structured explanatory model interview Cross countries comparison of TB related stigma: Malawi, India, Bangladesh, and Columbia Emic interviews with 100 pts in each country	Focus on stigma indicators
10	Balasegarama et al. (2008)	A survey of tuberculosis clinic provision in England and Wales. Public health & (Elsevier) Vol. 122 issue 6, p602-612	Focus on TB clinic staff survey
11	Heywood et al. 1999	A survey of pregnant women with tuberculosis at the port Mosby General Hospital. PNG Med J 1999 Sep-Dec; 42(3-4):63-70	Focus on prevalence, prenatal maternal outcomes rather than influences of early diagnosis
12	Craig, GM et al. (2007b)	The impact of social factors on Tuberculosis Management. The Authors. Journal Compilation. Journal of Advanced Nursing 61(4), p.418-424.	Focus on social factors hindering treatment

Author (left)	Citation (left)	Reason (left)	No.	Author (right)	Citation (right)	Reason (right)
Bothamley GH. et al. (2002)	Screening for Tuberculosis: the port of arrival scheme compared with screening in general practice and homeless. Thorax : 57; 45-49	Purpose unrelated to review	13	Bechurst et al. 2000	Factors influencing the distribution of tuberculosis cases in an inner London borough. Communicable Disease and Public Health Vol 3 NO 1March 2000	Focus on TB incidence not about care seeking
Ohcado et al. (2005)	The management for tuberculosis control in greater London in comparison with Osaka city: lessons for improvement of TB control management in Osaka city urban setting. Health Policy 73; p104–23	Not focused on TB diagnostic/treatment access	14	Story et al. 2007	Tuberculosis in London: the importance of homelessness, problem drug use and prison. [Thorax.bmj.com] - [Accessed 30, may 2008]	Focus on risk groups and not about access and care seeking
Maguire H. et al. (2002)	Molecular epidemiology of tuberculosis in London 1995-7 showing rate of active transmission. Thorax 2002; 57;617-622	Non TB care seeking	15	Gele et al. 2009	Pastoralism and delay in diagnosis of TB in Ethiopia. BMC Public Health, 9:5 http:www.biomedcentral.com/1471-2458/9/5	Pastoralist transient population with little access to HC facilities
Hayward, A, (2002).	The molecular epidemiology of tuberculosis in London, Epidemiol, Infet, 128, 175-184	Non TB care seeking	16	Soonthorndhada et al. 2004	Community Perceptions and Experiences of TB in Kancanaburi, Thailand: A gender equity analysis. Institute for population and social research. www.ipsr.mahidol.ac.th	Focus on community and TB patients' perception of TB
Underwood et al. 2003	Contact tracing and population screening for tuberculosis – who should be assessed?	Not specific to healthcare seeking by TB patients	17	Greenaway et al. 1999	Delay in Diagnosis among Hospitalized Patients with Active Tuberculosis—Predictors and Outcomes Am J Respir Crit Care Med Vol 165. pp 927–933, 2002 www.atsjournals.org	Focus on patients' outcomes of mortality and ICU admissions
Hawker, J. et al. (1999)	Ecological analysis of ethnic differences in relation between tuberculosis and poverty. BMJ 319: 1031-1034.	Purpose unrelated to review	18	DIMITROVA et al. 2006	Health service providers' perceptions of barriers to tuberculosis care in Russia.	Focus on perceptions of health workers
Bhatti, N, et al. J (1995)	Increasing incidence of tuberculosis in England and Wales: a study of likely causes. British Medical Journal, 310 967-969.	Focus on incidence and causes	19	Macg et al. 2007	Patient empowerment in tuberculosis control: reflecting on past documented experiences. Tropical Medicine and International Health, vol 12 NO 7 p. 873-885	Review of literature on patient empowerment model. Not met purpose of review
Brewlin P et al. (2006)	Is screening for tuberculosis acceptable to immigrants? A qualitative study. Journal of Public Health Volume 28, number 3 pp 253-260	Not specific to healthcare seeking by TB patients	20	Alvarez-Gordillo et al. 2000	Perceptions and practices of tuberculosis patients and non-adherence to therapy in Chiapas, Mexico, Salud Pub De Mexico 42(6):520-528	Focus on TB patients perceptions of TB and not experiences of health care seeking
Kumar D et al. (1995)	Tuberculosis among the homeless at the temporary shelter in London: report of a chest X-ray screening programme. J Epidemiol Community Health. Dec; 49(6):629-33	Target group active screening	21	Atun et al. 2005	Social factors influencing hospital utilization by tuberculosis patients in the Russian Federation: analysis of routinely collected data. Int J Tuberc Lung Dis; 9(10):1140-6	Focus on hospital utilization, not TB care seeking/access
Kothari et al. (2005)	Tuberculosis in Pregnancy – Results of a study in a high prevalence area of London. of tuberculosis among patients Europ Jou of Obst & Gynea My Vol. 126 Issue 1 p48-55	Focus on prevalence of TB in pregnancy	22	Balasegarama et al. (2008)	A survey of tuberculosis clinic provision in England and Wales. Public health & (Elsevier). Vol. 122 issue 6, p602-612	Non healthcare seeking

2. Narrative Review of Literature

Data Synthesis – Narrative Review   (in Portrait)
> Table 1 non-OECD Literature
> Table 2 OECD Literature

Data extraction sheet - (Table in Landscape)
> Table 3 Data extraction non-categorized

Data Synthesis – Narrative Review

Table 1 non-OECD - Narrative Review of Literature – Data Synthesis Table

Author	Country	Study aim to...	Data sources	Data Type	Study findings	Relevance to patients' experiences
1.Thorson et al. 2000	Vietnam	assess health seeking behaviour	CSS *Patients' response to questionnaire*	*Demographical and cough symptoms Objective*	*Paper highlights being women and choosing less qualified providers as barriers*	*Findings are not fully explored to reveal women' experiences of healthcare*
2.Grover et al 2006	India	understand influences of socio-economic factors and care seeking behaviour.	CSS *Patients' response to questionnaire*	*Socio demographic factors Objective*	*The study found that being an urban resident; being age 15 to 45, low socio-economic status as key influencers.*	*Emphasis on demographic differences not related to experiences*
3. Demissie et al. 2002	Ethiopia	determine delay by patient or provider.	CSS *Patients' response*	*Socio demographic factors Objective*	*Paper highlights that distance to health institute, knowledge about TB and treatment as determinant.*	*Distance from healthcare is related to lack of access*
4. Kiwuwa et al. 2005	Uganda	determine time taken to start treatment.	CSS *Patients' response*	*Socio demographic factors and health care contacts Objective*	*Paper found that daily alcohol consumption; being subsistence farmer; wrong perception about TB. Multiple Health encounters, cost of medical care, delayed referral by the HC., seeking help from government centres*	*Limited but patients' perception and providers' related delay in accessing TB treatments*
5. Ahsan et al 2004	Bangladesh	assess gender differences in treatment seeking behaviour.	CSS *Patients' response*	*Socio demographic / cultural and health care contacts data Objective*	*Being women with TB relationship problems with spouse and family members. More women not satisfied with their care providers' behaviour.*	*Findings revealed women's experiences of family and providers behaviour*
6. Togby et al. 2006	India	examine factors linked to patient and provider delay.	CSS *Patients' response to questionnaire*	*Patients' socio-demographical and health seeking behaviour Objective*	Patient delay: self-medication, choice of government doctors as first contact, use of traditional healers and cost of treatment. Health system delays were first contact with private doctors and cost of treatment.	*Self-medication traditional healers relate to patients but cost, and private care issues are providers related*
7. Sadiq et al. 2001	Pakistan	determine health care seeking behaviour and providers care.	CSS *Patients' response to questionnaire*	*Descriptive questionnaire socio demographical, symptoms, type of health care contacted Objective*	Most patients consulted within three weeks (77%) and delay was primary factor Prior to their consulting TB Centre, 96% patients had already reported to a health care provider, i.e., to first, second or third health care providers. Of 154 patients, 48 were diagnosed as TB and only 29 (19%) of them received anti-tuberculosis treatment.	*The results showed nearly half of those diagnosed did not start treatment from providers. Patients' related experiences are not specified.*
8. Godfrey-Faussett et al 2002	Zambia	determine risk factors associated with delay	CSS *Patients' response to questionnaire*	*Illness and cough, reason for chosen to attend the clinic and for delay, knowledge perception and belief Objective*	Delay was associated with older age, severe underlying illness, poor perception of the health services, distance from the clinic and prior attendance at a private clinic. No relationship between delay and knowledge about tuberculosis, nor with education, socio-economic level or gender and stigmatising attitude.	*The paper presumes that age, perception, distance and private clinic attendances determinant factors. Focus on association of delay rather than subjective experiences*

9. Van der Werf et al 2006	Ukraine	assess the magnitude of patient delay and evaluate risk factors for delay.	*Interviews & medical records* Patients' response to questionnaire and records	Face to face administered face to face questionnaire of risk factors and socio demographical data Objective	The main reasons for delay were 'thought symptoms would go away' and 'symptoms not considered serious 'unemployed with cough or loss of weight. The number of healthcare facilities visited before the start of TB treatment.	*The paper highlights patient-related illness experiences and also experiences of multiple healthcare contacts*
10. Peheme et al. 2007	Estonia	estimate health system delays	*Interviews* Patients' response to questionnaire	Social and demographic history of contact dates contacted dates of tests and diagnosis Objective	The factors significantly associated with HSD were: smear negativity, absence of cough among symptoms, absence of chest X-ray during the first visit and age >60 years. A significantly shorter HSD was determined in non-Estonians and unemployed patients. HSD was not associated with the specialty of the doctor first contacted by the patient.	*Findings are not fully explored to reveal patients' experiences of healthcare but estimation of delay using demographical and clinical variables*
11. Auer et al. 2000	Philipines	assess health seeking behaviour and quality of care.	*Structured Q* Patients' perspectives and responses to questionnaire	Narrative subjective & questionnaire Data	*Health seeking within a month. Self-treatment before seeking public healthcare facilities. Majority of patients had chest –rays and treatment unrelated to TB*	*Focuses on patients' and healthcare related actions rather than patients' experiences of them*
12. Sudha et al. 2003	India	identify influences of help-seeking	*In-depth Int* Patients' response to questionnaire	Socio demographic factors Objective	*Seeking from private health care providers; proximity to the residence; insufficient severity of symptoms; cost, work pressure; literacy.*	*Findings related to socio-demographical comparison are not sufficiently related to experiences*
13. Enwuru et al 2002	Nigeria	identify help-seeking behaviour	*CSS* Patients' response to questionnaire	Demographical and health care contacts Objective	*poor knowledge of TB symptoms and the causes of TB and most about transmission.*	*KAP based patients' illness experiences not related to actual experiences*
14. Huong et al. 2007	Vietnam	assess patient, health care provider delay.	*CSS* Patients' response to questionnaire	Demographic and distance from HC 1st health care contact and time since onset of cough and start of treatment; date of diagnosis. Objective	*Risk factors long patient delay: female sex, belonging to an ethnic minority, and living at > 5 km distance or in the northern area. Healthcare delay: urban setting, residence in the central area, initial visit to a communal health post, in TB hospital or the private sector.*	*Socio-demographic comparator of health actions and not related to patients' experiences*
15. Yimer et al. 2005	Ethiopia	determine length of treatment delay and factors	*SQI* Patients' response	Socio demographic and health care contacts data Objective	*First visit to traditional practitioner and self treatment. Prior attendance to health clinic.*	*Socio-demographic comparator of health actions and not related to patients' experiences*
16. Ngamvithayapong et al 2001	Thailand	describe health seeking behaviour, measure patient provider delay	*Interviews* Patients' response to questionnaire	Socio demographic, clinical Objective	*Lack of health insurance; a hill tribe ethnic group; no previous contact to hospital; lack of money. Being married and widower; HIV+ led to shorter delay. Provider delay was significantly higher in female patients than men.*	*Socio-demographic comparator of health actions and not related to patients' experiences. However, paper highlights inequity of provider care link to women*
17. Lienhardt. 2001	Gambia	estimate delay and identify risk factors.	*Structured interviews* Patients' response to questionnaire	Socio demographic and health care contacts data Objective	*Insufficient knowledge of TB by the providers. Pathways involved HC, TH, DS, Private Dr, hospital, Village HW, and friends and all considered as health provider.*	*Findings highlights multiple pathways to healthcare seeking and insufficient knowledge of providers*

18. Salaniponi et al 2000	Malawi	determine care seeking behaviour and diagnosis process	*Structured questionnaireP atients' response to questionnaire*	Patient knowledge, schooling and health care contact *Objective*	*Being unaware of their illness, due to poor schooling and lack of knowledge of TB. Seeking non-orthodox care providers.*	*Patients' related experiences of healthcare seeking not identified.*
19. Rajeswari et al 2002	India	investigate factors delaying diagnosis	*Semi-structured interview Patients' response to questionnaire*	Socio demographic and health care contacts data *Objective*	*Being an alcoholic, lack of awareness about TB. consulted government provider, live at distance, misuse alcohol. Longer health service delay if patient consult private provider.*	*Findings are limited to highlight patients' experiences of factors delaying diagnosis*
20. Maamary 2008	Syria	determine the determinants of delay in treatment	*Interview questionnaire Patients' response to questionnaire*	*Information from patient about delay and duration Objective*	*Living at far distance from HC. Stigma, Seeking care from traditional provider and multiple providers.*	*Living distance to healthcare related to lack of access Not clear the experience of stigma and care from multiple providers delaying treatment*
21. Pronyk et al 2001	South Africa	examine patterns of health seeking behaviour from hospitalized patients.	*Semi structured questionnaire response to questionnaire*	Socio demographic and experience of health service *Objective*	*Multiple pathways public hospitals, clinics, and also traditional healers and private GPs. Women remain undiagnosed for longer by health care.*	*Although women remain undiagnosed by healthcare their experiences are not clearly explored.*
22 Odusanya et al 2004	Nigeria	investigate patterns of delays before treatment	*Structured interview Patients' response to questionnaire*	Socio demographic and health service contact data *Objective*	. Delay associated with the patients (8 median days) where as Providers (2 median days) no association to any socio-demography, e.g. age, sex and educational level.	*Interesting information on the lack of association with socio-demographic factors and delay.*
23. Dos Santos et al 2005	Brazil	investigate factors associated with total delay.	*Interview Patients' response to questionnaire*	*Biological clinical, socio demographic and health care access, contact data Objective*	unemployment, having given up smoking, has lost weight and being treated in two of the six health districts. Age, sex, alcoholism and difficulty of access were not associated with delays,	*The lack of association with socio-demographic and delay. Findings are limited to highlight patients' experiences of health care in two districts*
24. Harper et al 2003	Gambia	investigate non-biological factors and diagnosis and treatment	Patients views and also community members and providers view	Patients knowledge of TB, gender, residence, source of help, migration and socio-economic factors	Gender, urban/rural residence, recourse of traditional healers, knowledge about TB, migration and socio-economic factors determinants	The paper focuses on non-biological factors that are not experience related
25.Macg et al 2004	Nicaragua	assess medical costs and delay to sputum test	*Interviews Patients' response to questionnaire*	*Socioeconomic, health status, cost incurred by the patient, and time to care utilisation and referral patterns. Objective*	more than one type of care giver, use of private practitioners. Spent more on medical care between the first visit to a care provider and the first sputum examination, more than 3 months on care pathway, poorly performing unregulated private care, delayed in reaching diagnostic facilities for TB.	*The study highlights cost incurred by patients and complex processes involved before diagnosis resulted from poorly regulated private care*
26. Aye et al. 2010	Tajikistan	investigate determinants of patient and provider delays	*Interview using questionnaire Patients' response to questionnaire*	sex, age, residence, durable assets, labour migration belief in curability of TB, use of self-treatment, sputum smear result, and the type of facility	The type of facility where patients made their first contact with the health system was the main determinant of health system delay. Those who first presented to peripheral primary care facilities also had relatively long delays.	*Findings are specific to peripheral primary care facilities as main determinants of delay. Limited to highlight barriers associated with these facilities.*

				first visited. Objective		
27.Meinntjes et al. 2008	South Africa	describe patient and provider delay and risk factors.	*Structured Questionnaire interviews & medical records* Patients' *response* to questionnaire.	interviewer-administered socio-demographic economic, symptoms, timing of health provider visited, knowledge, attitudes and beliefs. Objective	Factors independently associated with longer patient delay were: male gender, cough and first health care visit being to public sector clinic, rather than private general practitioner. Patient delay ≥ 14 days was associated with: increased need for transfer to a TB hospital. Provider delay ≥ 30 days was associated with increased mortality. Being male, cough and first contact public sector clinic; increased need for transfer to a TB hospital	Interesting findings from this study that being male and using public sector care. Nevertheless, reported delay and risk factors are limited to highlight barriers related to either to the patient or the providers' care.
28.Hui-Ping et al 2009	Taiwan	tuberculosis reporting enquiry system	Surveillance data Patients' records	Patients demographical data and data from clinical datasets diagnostic tests undertaken Objective	The main factors associated with diagnosis delay included age, reporting year, living with family and a positive sputum culture, increased age, an aboriginal ethnic background, a positive sputum culture and diagnosis at a nonmedical centre.	A much stricter definitions of delay a period of longer than 9 days was defined as a diagnosis delay and a period of longer than 2 days as a treatment delay.
29. Lawn et al. 1998	Ghana	determine the factors affecting the delay from the onset of symptoms to treatment.	Patients' response to questionnaire and clinical records	Socio – demographical data, duration of symptoms, dates of 1st consultation and consecutive events e.g. referral to chest clinic and case notes analyzed Objective	Doctor delay was significantly increased in females, rural patients, and among those needing hospital admissions. Increased doctor delay was strongly correlated with rates of failure to perform sputum microscopy ($r = 0.99$), low rates of diagnosis, and was seen particularly among private practitioners and rural government institutions.	Findings are specific to access and equity issues of healthcare rather than patient-related factors. Limited to highlight barriers associated with failures by healthcare to investigate TB particularly for women.
30. Fazlul Karim et al 2007(a)	Bangladesh	assess gender differences in delaying medical help.	Cross- sectional survey Patients' responses to questions	Narrative data Subjective employing quantitative/quali tative analyses	Older women had significantly longer patient delay. Conclusion Women has significant delay in help seeking behaviour.	The paper presumes that older women delay medical help. Findings are limited to highlight factors hinders women seeking healthcare
31. Liefooghe et al 1997	Kenya	understand beliefs perceptions and health-seeking behaviour.	Focus Groups Patients' views	Subjective Data	belief; Self treatment; Traditional healer; stigma fear by women in hospital and community. Treatment and diagnosis experiences	Interesting information on factors associated with patients and healthcare determining access to diagnosis and treatment
32. Eastwood & Hill 2004	Gambia	explore gender differences in care seeking and access	Semi-structured qualitative interviews. Patients' Views	Patient expressed data Qualitative Subjective	duration of symptoms, women consult traditional healers, not affording transport costs and treatment. Wrong perception and knowledge about TB. Stigma and lack of privacy to women.	Study highlights on factors associated with patients and healthcare. Moreover findings on stigma and privacy barriers in women are useful.

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33. Edington et al 2002	South Africa	describe belief, experiences of patients and treatment adherence	*Structured interview: Patients' Views*	*Socio demographic with patient expressed subjective data*	*Wrong belief about treatment, Belief, cultural norms TB treated by the THs; pollution, alcohol and smoking. Stigma, and access services, long waits, attitudes of HWs.*	*The study highlights that patients beliefs & norms as reasons However, lack of Pt. education, access and attitudes of health providers their experiences*
34. Johansson et al 2000	Vietnam	identify health seeking behaviour and gender differentials	*Focus group discussions Qualitative analysis using grounded theory approach. Patients' views*	*Participants' expressed views Subjective*	*Men tend to seek care from public health services. Women fear of isolation, stigma, poverty and low level education, concealment and denial of diagnosis, seek care from private providers, and self-medication. Professionals' attitudes, quality of services not met patients' expectations more in women.*	*Findings are specifically highlighted on gender differences in healthcare utilizations. Women's negative experiences of healthcare are not fully explored.*
35. Npang et al. 2007	Rwanda	identify beliefs and perceptions health-seeking behaviour.	*Patients' views*	*Interviewees illness narratives data Subjective*	wide use of herbal treatment for chronic cough in Rwanda. TB often mistaken for the acquired immune-deficiency syndrome (AIDS). Three health seeking end points emerge for chronic cough: home care, health facility and the traditional healer. Healers in some areas, however, believe TB due to witchcraft can only be treated traditionally.	*The study highlights factors led to self treatments and use of traditional healers care. From patients' distance from health facility and several trips to health facility before being screened for TB that were not clearly highlighted*
36. Asbroek et al. 2008	Nepal	examine pathways to TB diagnosis and treatment	*Semi-structured interviews, Patients' perspectives*	*Patients' story about illness and chronology of actions Subjective*	Patients factors: severity of complaints, inability to pay, peer support for choosing a provider, Poor quality, cost of provider, lack of referral, self referral due to lack of trust. Poor confidence in provider and lack of treatment results.	*Study highlights on barriers of pathways of access to TB diagnosis and treatment from patients experiences.*
37. Squire et al. 2005	Malawi	describe pathways to diagnosis, socio demographic characteristics	*Interviews Narrative research Patients' views perspectives*	*Critical incidents narrative and pathway to care Subjective Data*	Wrong perceptions about TB & HIV/AIDS and related stigma Different understandings of TB, its severity and potential treatment benefits Health system structural barriers were the main factors behind these pathways, requirement for hospital attendance, delays in symptom recognition, in receipt of sputum results, misconception of negative smears tuberculosis. Health system-related obstacles; Inappropriate handling of negative smears, Hospital admission or attendance,	*Narrative approach was used to understand pathways to reveal barriers of access to TB diagnosis and treatment from patients' experiences.*
38. Watkins et al 2004	Indonesia	explore factors affecting treatment seeking	*In-depth interviews Patients' views and perspectives*	*Patients' accounts of illness and health care experiences Subjective*	Treatments were inappropriate, limited and varying medications, symptomatic treatments over an extended period without diagnosis and treatments services delayed. Lack of awareness and little communication about	Findings from small number of cases interviewed highlights on a number of factors associated with the quality of the providers' care.

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					treatment. Defaulting treatment often associated with poor understanding and cost	
39.Needham et al. 2002	Zambia	clarify factors linked to patients' diagnostic delay	*Semi – structured interviews In-depth interviews Patients' response*	*In-depth interviews focusing on socio-economic and care-seeking data, time taken to contact. Subjective*	Financial constraints; on average 6.7 contacts prior diagnosis; travel at distance Being female sex, lower education, more than six instances of health-seeking encounters, outpatient diagnosis of tuberculosis, and visiting a private doctor or traditional healer.	The study highlights on socio-economic demographical differences. Nevertheless, the patients' healthcare experiences also pointed to multiple contacts that were not explored.
29 Gelaw et al 2001	Ethiopia	Understand social consequences of TB	Patients survey and perspectives through interviews	CSS using questionnaire survey and focus group interviews. Analysis statistical Objective	Negative attitude towards TB patients in the community. Good awareness of TB, and knowledge that TB is treatable. But some think TB caused by cold. Community knowledge about TB link with HIV/aids in the society. Most feel TB association with HIV makes it incurable, this in turn, contributes to social avoidance and stigma towards TB patients.	Study not relate to the experience of pathways to diagnosis and treatment.

Table 2 OECD Narrative Review of Literature – Data Synthesis Table

Author	Country	Study aim to...	Data sources	Data Type	Main findings	Relevance to patients' experiences
1. Calder et al. 2000	New Zealand	quantify interval to starting treatment.	Patients' and doctors' questionnaire response	Pre-coded questionnaire in order to measure interval (time-length) to diagnosis and treatment Objective	delay associated with smoking; hoped symptoms go away; fear of diagnosis; pre-existing lung disease, not assessing TB risk, multiple consultations.	Findings are limited to survey results to estimate time length unable to explore patients' fear, multiple consultations.
2. Sarmiento et al 2006	USA	identify pathways to diagnosis length for delays and reasons	Interviewer led patients response to questionnaire	Demographic, behavioural, health related information date of diagnosis, types of providers contacted, history of homelessness and reasons for delay Objective	Social, economic, structural, factors. Did not think it was serious, fear, cost in health care, transportation, no insurance, work. Long waiting times, lack of access, dissatisfaction with health care.	Findings are limited to key variables of researchers' interest in their measurements of patient and provider delays.
3. Farah et al 2006	Norway	assess the delays in the start of treatment.	record analysis	Clinical notes demographical, symptoms reported and review of notifications data Objective	Delay by NPTb cases; older age group higher in 45-59 age bands. Low index suspicion by clinicians in Norway.	Findings are limited to researchers' interest in their assessment of delays from records.
4. Ward et al 2001	Australia	investigate the patient and provider delays.	Patients' records	Demographical, migrant status, length of stay, history of TB, dates of diagnosis and treatment Objective	Migrants from high prevalent countries had shorter delay than older age groups & long-term resident migrants. Failure to perform appropriate investigation, misdiagnosis of chest X-rays, ineffective treatment, delaying TB tests, misdiagnosis, test failure, treatment delay.	Findings are limited to demographical differences oaf PTs. Interesting information on barriers linked to providers' care.
5. Sherman et al 1999	USA	examine factors associated with patient and provider delay	patients records and medical records	Demographic, clinical information and history of TB through telephone interview and from medical records. Objective	Age 55-64 years, primary language other than English factors for patient delay. not having chest X-ray at 1st visits; absence of cough; negative smear results associated with provider delay.	Findings are limited to variables of researchers' interest rather than their experiences.
6. Moudgil et al 1994	Scotland UK	determine the incidence and delay PTb by ethnic groups	Patients' records	Clinical records review of type of TB, patients' ethnicity and dates of health contact and diagnosis. Objective	Delay for lymphatic TB was significantly longer for Non Caucasians (mean 26 weeks range 0-156)	Findings are limited to patients' type of TB and delay rather than their experiences of process of diagnosis.
7. Lewis et al 2003	England UK	examine the duration and possible causes of delay	Patients' records	Health care records of patients and review of clinical data and dates of diagnosis Objective	Prolonged delay in cervical lymph node. Pulmonary TB associated with shorter delay. Patient delay estimated 9 weeks median delay (range 0-104 weeks) vs. health care median delay 5 weeks (0.5 – 210)	Findings are limited to patients' type of TB and delay rather than their experiences of process of diagnosis.
8. Rodger et al 2003	England	estimate delay in diagnosis and investigate factors	Patients' records	Surveillance data collected by the patients' doctors: ethnicity, age, birth place, gender type, time of entry in UK Objective	Factors associated with delays were more likely for white patients, and women.	Findings are limited to patients' demography rather than their experiences of delay.
9. Gibson et al 2005	Canada	examine socio-cultural factors influencing	Group interviews Patients' Views to explanatory	Group views about causes of TB stigma and TB, sources of information on TB, treatment	TB linked to 'vice', life-style; living in unhealthy condition environment. Cultural influences in immigrants and aboriginal populations. Experience of health care stigma,	Findings are limited to patients' demography rather than their experiences of

		behaviour in TB treatment	questions	experiences. Subjective	TB side effects, lack of knowledge of TB treatment. Fear of diagnosed with TB.	delay.
10. Nnoaham et al 2006	England	describe perceptions and experiences of patients .	Patients' views and experiences	Questions about patients' perceptions and knowledge of their illness aetiology, treatment probed for additional detail Subjective.	Key themes: Misinterpretation of early symptoms. Denial of the diagnosis, good treatment adherence link to role of TB specialist nurses in promoting adherence. Felt stigma no experiences. Diagnosis, in weeks ranging from 2 weeks up to 40 weeks. Time to start of treatment, from 1 to 9 months	Key findings summarized were not linked to reported delay patients' accounts revealed barriers linked to GPs' care in London.
11. Leung et al 2007	Hong Kong	measure patients and providers delay	Patients responses to nurse administered questionnaire and notification records	Demographic data, date of first contact, initial investigations, number of contact s, first diagnoses TB, and date of treatment; sputum smear and culture, radiological findings.	Unemployment independently predicts longer patient delay and haemoptysis as shorter delay. Patient over the age (>60) years and unavailable radiological bacteriological evidence delaying diagnosis and treatment (provider delay).	Findings are limited to key variables of researchers' interest in their measurements of patient and provider delays.
12. Paynter et al 2004	England	measure patient and health care delays .	Notifications data from chest clinic and from GPs through postal questionnaire	Date of onset of symptoms, date and health care site of first point of contact, referral to chest clinic. Objective	Shorter delay with PTB, young patients. TB patients presenting at the A&E, born in high prevalence country. Referral from GP to X-ray test, waiting to see chest clinic staff associated with HC related delay.	The study has not highlighted any particular patients' factor contributed to the delay.
13. Storla et al 2008	World wide	Review of evidence on delay	Review of primary research articles	Systematic search using research data bases outcome of interest was delay in diagnosis and treatment. Objective	HIV, chronic cough/other lung diseases, low access (geographical or socio / psychological barriers), initial contact with low level health care facility, private practitioner or traditional healer; old age; female-sex; alcoholism; and substance abuse, history of immigration, low educational level, low awareness of TB, incomprehensive beliefs, self treatment, and stigma.	vicious cycle of repeated visits to same provider, nonspecific antibiotic treatment, failure to access TB tests. After diagnosis, TB treatment provided quickly
14. Sagbakken et al. 2010	Norway	explore experiences of being diagnosed and diagnostic delay.	Patients experiences TB Registry, clinical case notes from hospitals, and referral notes	Patients' experiences of diagnostic process; the disease; social support from patients' description. Subjective	Patients experienced the diagnostic process took months, even years, diagnosis difficult to confirm, health professionals' difficulties in associating symptoms with TB, delays the diagnostic tests for TB extra-pulmonary TB.	The study highlights that the accounts of migrants experiences of diagnostic delay in Norway.
15. Marais 2006	England	investigate structural influences in the local context.	Patients experiences of TB services	interviews with migrant Africans with experience of TB treatment, knowledge of TB, stigma, information sources, access to GP, referrals to specialist, and access to treatment.	Lack of access to a specialist care; reluctance of GPs to refer, refusing referrals to asylum seeker, temporarily registered. Several weeks of ineffective antibiotic therapy, GP's failure to investigate several weeks to 6 months, self referral to the local TB Clinic, reluctance to seek GP for health advice, GP's lack of knowledge about TB, no confidence and trust.	The study highlights that the accounts of small number of patients' barriers related to GPs' care in Westminster London.
16. Metcalf et al. 2007	Wales UK	understand the process of diagnosing in primary care.	Patients experiences from their accounts and GPs accounts of diagnosis process	Patients' account of their health prior diagnosis, during contact with health services, their views of their diagnosis. GPs' account of TB diagnostic process of their patients' referring to case notes as well as to reflect on TB and care more generally. Subjective	atypical presentations and low clinical suspicion of TB, lack of continuity of care, workload demands, suboptimal doctor and patient communication.	Relatively small number of patients' and GPs' accounts revealed barriers specific to GPs' care in south east Wales UK.

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17. Okur et al 2006	Turkey	investigate patterns and reasons for delays .	Patients response to questionnaire (unclear how it was administered) and patients' clinical notes.	Clinical files of the patients and a questionnaire data demographic social status, first symptoms and diagnosis and treatment intervals from notes. Objective	There was a delay in consulting a physician by 49% of patients. A low index of suspicion for tuberculosis on the part of the physician and healthcare system and laboratory delays were the most common reasons for delays in diagnosis.	Findings are drawn from patients and records to indicate barriers associated with providers' diagnosis processes.
18. Gershon et al	Canada	estimate delays in TB treatment and examine factors	Surveillance data reported from providers	Time to TB treatment and the date of treatment initiation from healthcare provider and/or public health providers.	Time periods longer to treatment independently associated with middle-aged Foreign-born patients in Canada more than 10 years patients with non-pulmonary disease and patients managed in some health districts.	Findings are limited to key variables of researchers' interest from surveillance datasets.
19. Cummings et al. 1998	USA	determine treatment outcomes	Patients reported to Department of Health in 1993	Patients' characteristics age, residence, place of diagnosis, history of homelessness, and patients' movement. Objective	Diagnosed TB in state prisons; abuse drugs; alcohol, homelessness; movement more often by patients Prisons emerged as the strongest risk factor for defaulting from treatment.	Findings are limited to key variables of researchers' interest found in surveillance data.
20.Goulb et al . 2005	USA	assess implications of antibiotic treatment on delays frequency of chest radiographs (CXRs)	Patients response to questionnaire & Medical records	Patients' Health care Interaction for their TB symptoms and details of health care visits regarding their present illness. Patients' medical records to confirm diagnostic tests, and medications offered.	The researchers found that patients who received antibiotics prior to TB diagnosis had a diagnostic delay that was twice as long as that of patients who did not receive antibiotics. Moreover, the delay was similar regardless of the antibiotic class prescribed.	Findings are drawn from patients and records to indicate barriers associated with antibiotic treatment prior diagnosis.
21. HO- M-J et al 2004	USA	investigate the health-seeking behaviour patterns	Patients views and stories	Illness narrative and experience through questions symptoms, course of sickness, and treatment and Subjective	Patients sought care from physicians, traditional practitioners, fewest referrals to DOT program. Illness narrative reveals that reason for patients' choices of provider related to its convenience.	Interesting to note patients' experiences of care choice based on convenience and providers' referral problems
22.Diez et al. 2005	Spain	investigate HSD and associated factors .	Clinical records	Clinical information collected from their clinical records first contact with health care, diagnosis and first date treatment was prescribed. Objective	HSD was associated with: age .44 years, intravenous drug use, diagnosis at a primary care centre, prior preventive therapy, presence of silicosis or neoplasia, symptoms, related to gastrointestinal site.	Findings are limited to key variables of researchers' interest found in clinical records.
23.Gagliotti et al 2006	Italy	quantify patient and health care delays and using migration status.	*Prospective surveillance data* Patients' response to questionnaire	*Demographical surveillance / TB symptoms onset, first consultation with provider, date of initiation of treatment.* Objective	Migration status; Italian patients had longest HSD (60 median days) Where as recent migrants <3 years the longest pt patient delay (16 median days). Migration status was independently associated with both patient and health care delay, although the direction of association changed according to which delay was considered.	*Findings are limited to highlight barriers in those with migration status reported to have delayed more.*
24.Sreeramar eddy et al 2009	World wide	summarize data on delays in diagnosis .	Research articles	Review of findings from 52 primary studies duration of patient, health system and total delay	Both patient delay and health system delay in low income countries (31.7 days and 28.5 days) were similar to those reported in high income countries (25.8 days and 21.5 days).	The review is limited to gathering evidence of measured delay rather than the barriers to delay
25. Smith et al 2006	England UK	examine frequency attended the in A&E and diagnosis	A&E clinical records	Patients attendance in the A&E for 6 months prior diagnosis ethnic origin, age, risk factor, admission, test results	No access to a general practitioner; self-referred to A&E. Nearly a third of patients diagnosis missed in A&E, 69% of patients required admission, diagnosis was quicker in	Findings are limited to A&E attendances of clinical notes rather than

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				and length between attendance and diagnosis. Objective	most A&E attendances. Failure to suspect TB, symptoms not typical of TB, or experiencing non TB symptoms	patients' experiences of delay.
26. Waisbord 2004	World wide	Summarize what is known about behavioural barriers to TB control	Medline searched Research articles not quantified	Review of findings from 52 primary studies duration of patient, health system and total delay	Patients' care-seeking behaviour, gender, urban/rural residence, knowledge about TB care and cure, and socio-economic factors. Providers' lack of diagnostic tools in health clinics, insufficient knowledge and neglect , poor quality of care not diagnosed, poor communication of healthcare providers.	The review highlights that identifying behavioral and structural barriers in a continuum from first symptoms to TB treatment
27. Gerrish et al. 2010	England UK	to gain insight into sociocultural influences on TB prevention, diagnosis and treatment of the disease.	Patients experiences of TB services	interviews with Somali ethnic patients' experience of TB treatment, knowledge of TB, stigma, information sources, access to GP, referrals to specialist, and access to treatment.	All pts. visited their GPs when they felt unwell. The cultural beliefs, stigma . language barriers, Frequent change of addresses and lack of stability hindering medication intake A lack of trust and confidence in healthcare providers, GPs lack of time to diagnose TB, language barriers, Numerous contacts concerns had not been treated seriously by their GPs, atypical symptoms diagnosis had taken longer and.	The study highlights that the accounts of small number of patients' barriers related to GPs' care in Liverpool.

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Table 3 Data Extraction Table non Categorized

Authors	Study aim	Settings, Populations and Samples	Method/Framework and Analysis	Findings and themes	Strengths and weaknesses
1. Thorson A et al 2000	To assess health seeking behaviour in adults with long term cough	**Vietnam** Adults with cough more than 3 weeks	CSS Population based survey (Prevalence)	The paper highlights delayed pathways for women rather than men. Women took more health-care actions than men, but chose less qualified providers and reported lower health expenditure per visit.	The paper highlights possible gender inequity in health care provision.
2. Auer et al 2000	To assess health seeking behaviour perceived causes of illness and quality of care.	22 health centres in, Metro Manila **Philippines** From 319 sputum smear +ve pts Male 70% and Women (30%)	A semi-structured interviews including questionnaire items of self report	More patients sought help from health care within a month, to health centre or private doctors first. Majority had chest X-rays over half had treatment not related to TB by their doctors and some purchased anti-TB drugs before seeking help from governmental health services. .	The paper highlights that being kept on inappropriate medication delaying pathways to diagnosis and treatment. This may signify miscommunication b/n patents and doctors
3. Liefooghe et al 1997	To understand beliefs perceptions of TB, and health-seeking behaviour.	Uasin Gishu **Kenya** Five focus groups interviews one group of hospitalized TB patients (8 male)	FG community beliefs and values using trained mediator	TB was associated with HIV or asthma; belief in familial inheritance; fear of isolation in females; Self treatment; Traditional healer; Treatment experiences; stigma associated with hospital Isolation and community. Incorrect diagnosis led to delay;	Not specifically relating factors to patients pathways particularly for the 8 patients interviewed in their group.
4. Grover et al 2006	To understand the influences of socio-economic factors and patient help-seeking behaviour.	Urban & rural communities in North India 200 chest symptomatic	**Cross sectional survey** Statistical analysis comparison of demographical factors and health care seeking	Urban respondents resorted to self treatment than rural; age 45-64 groups sought medical help more than 15 to 45 age groups, low socio-economic status & being younger age with symptoms significantly associated with delay.	Study could not identify barriers and facilitators more clearly
5. Demissie et al. 2002	To determine delay attributed to the patient or provider.	Addis Ababa **Ethiopia** 700 TB patients	**Cross – sectional survey** closed and open ended questions	There was no significant difference in socio-demographic factors Distance from home to health institute, knowledge about TB treatment among the smear negatives. Longer health service delay (delay more than 15 days) was associated with far distance.	Distance from health care facilities and knowledge of TB symptoms amongst smear –ve TB patients. No significant differences in socio-economic variables.
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7. Sudha et al. 2003	To identify factors that influence help—seeking	Tamil Nadu South **India** 649 chest symptomatic in rural and urban settings	**In-depth interviews** Analysis of urban and rural patients using sex, age, literacy, income and previous TB treatment variables as comparator.	Private health care providers; proximity to the residence; insufficient severity of symptoms (in those did not seek care); cost unaffordable. Lack of time due to work pressure; literacy and family income	Not specifically examine patients' experiences of pathways after contacting health care
8. Enwuru et al 2002	To identify help—seeking behaviour patterns	Chest clinics in Lagos **Nigeria** 168 newly diagnosis with TB.	No description of the tool used. The study offer a correlation between KAP and Health care seeking behaviour	The study highlights delayed pathways associated with poor knowledge of TB symptoms and the causes of TB… Only 16 patients presented at 4 weeks knew about TB and most about transmission. The remaining 105 patients presented at 12 weeks did not know about TB.	limitation on bias findings as it did not seek to identify other barriers
9. Kiwuwa 2005	To determine for the time taken to	Kampala Mulago national Hosp	**A cross-sectional survey** using pre-coded questionnaire	Common independent predictors of patient delays: **daily alcohol** consumption; subsistence farming; **wrong** perception about causes of	However, the authors described the socio-

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Author / Year	Objective	Setting / Sample	Method	Findings	Highlights / Notes
	start treatment.	Uganda 231 newly diagnosed smear +ve patients		TB. i.e. smoking. In regards to HD the study highlights that >2 health seeking encounter per month, cost of medical care, prolonged before referral to diagnostic centre by the HC staff. The study highlights majority sought help from pharmacy and private clinic those approached governmental centres had the longest delays	economic variables as patients' experiences of delay appear not clear as they did not identify why patient chose non-governmental facilities rather than public HC facilities.
10. Ngamvithayapong et al 2001	To describe health seeking behaviour and measure patient provider delay	Chiang Rai province Thailand 557 new smear +ve TB patients	**Interview using structured questionnaire**	Patient delay: linked to no health insurance; being a hill tribe ethnic group; no previous contact to hospital; lack of money. **Being married and widower**; HIV+ led to shorter delay. Provider delay was significantly higher in female patients than men. Overall delay associated with the patients (>21 days) and providers (>7 days)	The paper was inconclusive of why delay was common to female patients. This is associated with Providers
11. Lienhardt. 2001	To estimate delay and identify risk factors.	Rural and urban HCs in **Gambia** 152 TB pts. Median delay was = 8.6weeks	**Structured interviews**	Median delay was longer in rural pts (12 weeks). Delay was shorter in young pts. Delay was associated with the provider delay to treatment accounts to (8.6 weeks). **Insufficient knowledge of TB by the providers**. Unique to this study is the pathways involved HC, TH, DS, Private Dr, hospital, Village HW, and friends and all considered as health provider.	The paper highlights the health service related delay as main factor. Analysis of data involved statistical, not significantly provide information on pts. Experiences, choice etc...
12. Ahsan et al 2004	To assess gender differences in treatment seeking behaviour.	Rural communities in **Bangladesh** Median patient delay 63 days.	**Descriptive cross-sectional study** Analysis using statistical quantitative method using socio cultural, demographic, and health care service factors	Significant gender differences in delay. Majority of women delay more than men, 50% of women delay TB diagnosis and treatment over 60 days. Avoid being labelled as TB patients. Relationship problems with spouse and family members. 40% of women and male (24%) not satisfied with their care providers' behaviour.	The paper highlights treatment seeking behaviour for example 50% women preferred traditional healers to keep secret may be to avoid conflict as most women(66%) were married (gender violence)
13. Fazlul Karim et al 2007(a)	to assess gender differences in delaying medical help.	In 10 sub-districts in **Bangladesh** 1000 newly diagnosed TB patients	**Cross- sectional survey**	Pt longer mean and median delays for women and men Gender associated with longer pat delay and health care delay. Older women had significantly longer pat delay. Conclusion Women has significant delay in help seeking behaviour.	Women experienced longer delay in various stages of their pathways
14. Calder et al 2000	to quantify and examine the interval between initial symptoms and starting treatment.	Auckland **New Zealand** 100 patients and their doctors.	Interviews using questionnaire with patients. Doctors were surveyed about patients treatment, therapeutic and referrals	Patient delay was associated with smoking; reported country hoped symptoms go away by its own; fear of what would be found on diagnosis; (.......) Longer doctor delay associated with pre-existing lung disease, not enquiring TB risk, multiple consultations. (......)	The paper highlights longest delay by providers
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16. Yimer et al. 2005	To determine the length of treatment delay and analyze factors	Amhara region **Ethiopia** 384 smear +ve PTB pts	**Semi-structured questionnaire interview** on day of diagnosis and logistic regression analysis of data	First visit to traditional practitioner and self treatment by the patient. Health care delay contributed significantly to the total delay median=80 days. Prior attendance to health clinic was associated with increased health system delay and did not vary by age or sex.	Prior visit a health post / clinic or a private doctor significantly associated with health care delay
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Study	Objective	Setting/Sample	Method	Findings	Comments
18. Salaniponi et al 2000	To determine care seeking behaviour and diagnosis process	**Malawi** 1,099 pulmonary TB cases	**Structured questionnaire.** Analysis of demographical data using Epi-Info X2 test	Median delay between onsets of symptoms to diagnosis was 8 weeks and 7 weeks to submission of sputum.70% sought care from local medical care and 30% traditional healers. Nearly half of these patients were unaware of their illness, significantly associated with poor schooling and lack of knowledge of TB. Delay associated with visiting non-orthodox care providers.	Low level providers of care community poor knowledge about TB.
19. Rajeswari et al 2002	To investigate factors associated with delaying diagnosis	**South India** In 4 districts in 531 new smear +ve patients	**Semi-structured interview** using a structured questionnaire and multivariate analysis	Lack of awareness of TB. Men postponed RX for longer period initially consulted a government provider. Resided at distance Being an alcoholic. Lack of awareness about TB. Men postponed seeking care. In analysis the study highlights long patient delay is higher if the patient consulted government provider, live at distance, misuse alcohol. Longer health service delay if patient consult private provider.	Longer patient delay associated with government provider. More than a month. Longer health service delay associated with private provider. 23 days The study apply patients' demographical factor to assess both types of delay.
20. Maamary 2008	To determine the extent and determinants of delay in diagnosis and treatment	**Syria** 800 new smear +ve cases	**Structured tested interview** questionnaire	Living at far distance from HC. **Stigma** associated with TB Seeking care from traditional provider and from multiple providers. The mean total delay 80.4 days	Main delay associated with the patient rather than health service.
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22. Eastwood & Hill 2004	To explore gender differences in care seeking and access to treatment	**Gambia** 15 HWs And 30 TB patients 15 female and 15 men	**Semi-structured qualitative interviews.** Data analyzed thematically	The duration of symptoms at presentation to medical services ranges from 2 months to 3 years median of two months for both men and women. Most women consult traditional healers. Problems of affording transport costs and accessing treatment. Negative perception of TB; lack of knowledge about TB. Stigma particularly more on women and lack of privacy to female patients	**Not specifically investigated the duration from seeking care to starting treatment.**
23. Edington et al 2002	to describe belief and experiences of patients presentations and treatment adherence	Tintswalo district **South Africa** 303 patients 1st interview 286 pts 2nd interview 3rd interview 189 pts	**Structured interview:** individual patient interviews at first contact, 2 months and end of treatment (n=303, 286, 186 respectively), The focus group interviews (n=14 groups of 160 individuals patients and community groups)	Belief that TB caused by breaking cultural rules: abstinence of sex after the death of family member & after the woman have spontaneous abortion. TB can only be treated by the THs; Western type of TB caused by pollution, alcohol and smoking. Stigma, and difficult accessing services, long waits, attitudes of HWs. A number of factors that is related to female patients providers included: belief that abstinence from sex while on treatment (misunderstanding about treatment and needs), difficulties in accessing medical help, long waits, unacceptable health professionals' attitudes (not known how many patients) Access and long waits related to hospital care	The study only highlights potential barriers associated with patients' belief, stigma, and health service factors. The emphasis of the research is on patients and community perceptions rather than relating factors in the pathways.
24. Pronyk et al 2001	To examine patterns of health seeking behaviour from hospitalized patients.	Bushbuckridge region **South Africa** 298 hospitalized patients	**Semi structured questionnaire** Coded answers and text responses and use of non-parametric proportional comparisons. Text responses not thematically presented.	The findings highlight delay associated with the patients (median 9 weeks) than health providers (median 1 eek). Pathways involved, public hospitals, clinics, and also traditional healers and private GPs. Pulmonary patients delayed between the onset of symptoms and diagnosis. Women remain undiagnosed for longer. Significant delay was attributed to the health acre delay particularly for women.	The study examines factors in relation to demographic, i.e. family size and distance, years of education. The rate of diagnosis was slower for females and lives at distance and little can be known of barriers from patients' experiences.

	Aim	Setting/Participants	Method	Findings	Conclusion
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26. Johansson et al 2000	To identify perspectives of TB patients on health seeking behaviour assessing gender differentials	Vietnam urban and rural residents 16 focus groups ??? composition and no of participants	Focus group discussions Qualitative analysis using grounded theory approach.	Gender differences in help-seeking behaviour. Men tend to seek care from public health services. Delay in women was associated with fear of isolation, stigma associated with poor SE status and level of education and concealment and denial of diagnosis. Women tend to seek care from private providers, and self-medication. Professionals' attitudes and quality of services did not meet patients' expectations and women were sensitive of these factors in particular.	The study highlights gender inequity in providers care likely hinder women seeking care from public health care services.
27 Odusanya et al 2004	To investigate patterns of delays before treatment	General hospital Lakeja Lagos **Nigeria** 141 patients recruited, 116 were smear + and 117 delayed more than a month for treatment	Structured interview with patients on interval between symptoms to seeking health care	Information collected on socio-economic and demographic patient specific data and information on onset of symptoms, 1st visit to any source for help, data of diagnosis. Patient delay was not associated to any socio-demographic characteristics, age, sex and educational level. Information gathered is onset of symptom, date of first contact to health care diagnosis and start of treatment and also demographical variables. Delay associated with the patients (8 median days) where as Providers (2 median days)	Majority of patients sought help from private and chemist (54%) government facilities (31%). The obvious limitation of the data it did not capture patients' reasons for choosing their first contacts and for the delays they experienced.
28. Gerrish et al. 2010	to gain insight into sociocultural influences on TB prevention, diagnosis and treatment of the disease.	Patients experiences of TB services	interviews with Somali ethnic patients' experience of TB treatment, knowledge of TB, stigma, information sources, access to GP, referrals to specialist, and access to treatment.	All pts. visited their GPs when they felt unwell. The cultural beliefs, stigma . language barriers, Frequent change of addresses and lack of stability hindering medication intake A lack of trust and confidence in healthcare providers, GPs lack of time diagnose TB, language barriers, Numerous contacts concerns had not been treated seriously by their GPs, atypical symptoms diagnosis had taken longer and.	The study highlights that the accounts of small number of patients' barriers related to GPs' care in Liverpool.
29 Gelaw et al 2001	Understanding attitude and social consequences of TB rather than barriers/facilitators	Addis Ababa **Ethiopia** 7 03 participants, 326 males and 377 women	Cross-sectional survey using questionnaire survey, and focus group interviews. Analysis is based on statistical proportion comparison	Negative attitude towards TB patients in the community. Good awareness of TB, and knowledge that TB is treatable. But some think TB caused by cold. Community knowledge about TB link with HIV/aids in the society. Most feel TB association with HIV makes it incurable, this, in turn, contributes to social avoidance and stigma towards TB patients.	Study not relate to the experience of pathways to diagnosis and treatment.

Table 3. Non Categorized Literature Review Data Extraction Table

Authors	Study aims	Settings, Participants and Samples	Method/Framework and Analysis	Outcomes / Findings	Strengths and Weaknesses
30. Samiento et al 2006	To identify pathways to diagnosis and determine time length for delays and reasons	Harlem hospital DOT programme in **New York**.39 patients over the age of 18 years Male =27 and Female= 12	Cross-sectional survey of help-seeking behaviour using semi-structured interviews. Analysis using comparative predictive factors employing statistical test and significance testing.	Reasons given by the patients: Social, economic, structural, factors. Did not think it was serious, fear of something serious, cost of health care, transportation, lack of insurance, busy not getting time off work. Reported patient related delay = 10.5 weeks on average. Reported health care related delay =7.5 weeks on average. Long waiting times, lack of access, dissatisfaction with health care. The research highlights that No association b/n delay and HIV status, substance use, HX incarceration, demographic factors Qualitative question able to reveal broadly on factors.	The extracts from two patients presented highlighted 3 months delay by the first patient who thought illness not serious and in the second patient who presented four times and her symptoms attributed to bronchitis by her doctor and referred as chronic bronchitis and diagnosed with TB.
31. Guled Farah et al 2006	To assess the delays in the start of treatment.	**Norway** Retrospective record analysis for 83 patients: 71 born abroad and 12 born in Norway. 189 cases = 83 case included 57 (pulmonary) and 26 (NP Tb)	Analysis of clinical records: TB registry, clinical notes, referrals providers' data using regression analysis on factors that was important for the researchers.	Analysis of data from records of reported symptoms, age, type of TB, birth place. Patient delays (median 28 days) significant in NPTb cases; in the older age group higher in 45-59 age bands Providers delays (median 33 days) longer for those born in Norway noted as could be due to low index suspicion by clinicians (assuming low prevalence in Norway).	No assessment of barriers associated with providers. Possible bias associated with clinical records and providers 'clinical emplotment'.
32. Ward et al 2001	To investigate the patient and provider delays in Queensland.	Queensland Australia 758 symptomatic smear +ve TB patients records of bacteriological and histological confirmed	Comparison of patient delays with health care delay. Data analyzed using regression analysis on factors that were important for the researchers.	Analysis of records of bacteriological and histological confirmed Delays associated with patients were median 30 days. Migrants from high prevalent countries and Australians had shorter delay than non-indigenous Australians: the were and in older age groups & long-term resident migrants. For Health system delays were median 22 days. For smear positive groups delays median days 30 days vs. 11 days respectively. The study highlights several provider related factors. Failure to perform appropriate investigation and misdiagnosis of chest X-rays, ineffective treatment and delaying tests, misdiagnosis with other conditions, test failure, treatment delay for 27 patients.	Although, there are obvious limitations in the assessment of barriers associated with patients and providers from clinical records. These researchers however have highlighted some barriers associated with the patients (n=32) and providers of (n=27) patients.
33. Sherman et al 1999	To examine factors associated with patient and provider delay	In the five boroughs of New York city 138 pts who had +ve cultures and 131 of whom sought help in their boroughs	Retrospective medical record review & patients' interview analysis did not provide qualitative data analysis.	Age 55-64 contributed to longer delays. Primary language non English 50% of subjects sought care within 25 days. Median patient delay was 25 days. Age 55-64 years, primary language other than English factors for patient delay. Median provider delay was 15 days homelessness, not having chest X-ray at 1st visits; absence of cough; negative smear results associated with provider delay.	The study highlights age and language barrier associated with patient delays. However it would have been useful if the accounts of these patients included for understanding issues in support of their findings.

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Study	Aim	Setting/Sample	Method	Results	Comments/Limitations
34. Moudgil et al 1994	To determine the incidence and delay in diagnosing extra PTb by ethnic groups	Lothian **Scotland** 87 patients: 59 Caucasians and 28 non-Caucasians.	Records analysis	Delay for lymphatic TB was significantly longer for Non Caucasians (mean 26 weeks range 0-156)	No subjective data on barriers or facilitators. Assessment of delay using objective data type of TB and ethnic origin.
35. Lewis et al 2003	To examine the duration and possible causes of delay	**London** Newham health care district Records of 93 patients	Audit – Patient delay vs Health care delay	Prolonged delay in 3 patients with cervical lymph node. Pulmonary disease was associated with shorter delay. Patient delay estimated 9 weeks median delay (range 0-104 weeks) vs. health care median delay 5 weeks (0.5 – 210)	The obvious limitation with the study the evidence provided on barriers or facilitators with various form of TB. Assessment of delay using objective data type of TB and ethnic origin is limited to understand factors clearly.
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38. Rodger et al 2003	To estimate delay in diagnosis of tuberculosis and investigate factors	**London** 1355 TB patients with smear+ result – result obtained for 853 (63%).	Retrospective case notes analysis for 853 patients.	Median delay was 49 days (14-103) Factors associated with delays were more likely for white patients, and women. Age and birth place were not independently associated with delay.	Similarity b/n those information obtained and unavailable for age, sex, ethnic group.
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41. Gibson et al 2005	To examine a complex set of socio-cultural factors influencing behaviour to TB prevention and treatment	Alberta **Canada** TB clinics. Foreign born groups involving those with a history of TB. (n=103). The aborigines group from the roster of health clinic in each community (n=30)	Semi-structured Interviews Klein man (1981) illness explanatory model + Trinidis's (1994)	TB caused by 'vice', irresponsible life-style; and living in unhealthy environment. Socio-cultural factors influencing prevention and RX of TB in immigrants and aborigines populations. Health care stigma felt by the some aborigines' people. Experience of TB side effects and lack of knowledge about treatment. Fear of missing family and not even getting the mails if diagnosed with TB.	The study highlights the lack of knowledge strong association with negative attitude to TB and worse experience with the disease. It is not clear how these factors identified led to delaying care particularly factors associated with stigma by health care staff and side-effects of treatments.
42. Nnoaham et al 2006		Homerton hospital in Hackney East **London** 18 patients receiving treatment for TB invited 16 agreed to participate.	**In-depth interviews** All patients self presented to health care services, and not identified by active case finding.	Misconceptions about TB: thinking hereditary, poisoning and pneumonia, sharing cutlery, having sex with sufferers. Symptoms misinterpretation: Flu, boils, food poisoning, strenuous activity resulting delay in seeking care. Denial of diagnosis: Felt stigma; HIV cross stigmatization of TB: Most sufferers offered HIV test felt stigma, and declined HIV test.	Relatively small number of African ethnic patients interviewed. Findings are not specifically highlighted to the extent of barriers associated to the providers.
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44. Leung et al 2007	To measure patients and providers delay	TB registry in **Hong Kong** 1,662 patients with pulmonary disease. Median patient delay = 20 days Ethnicity	Retrospective structured questionnaire applying systematic sampling.	The median delay associated with the patients delay 20 days (7-37 days) and providers delay 20 days (6-55 days). On multivariate analysis. Unemployment independently predicts longer patient delay and haemoptysis as shorter delay. Patient over the age (>60) years and unavailable radiological bacteriological evidence delaying diagnosis and treatment (provider	The demographic factors collected only for 1249 patients for 413 patients unaccounted for. Whilst provider delay associated with lack of TB specific test was

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Author / Ref	Aim	Setting / Sample	Methods	Results	Comments / Weaknesses
		Chinese, white, Asians		delay).	useful it would have been useful to clarify the accounts of unemployed delayed longer to constitute patient delay.
45. Paynter et al 2004	To measure patient and health care delays in treatment of PTb.	North Middlesex University Hospital London Retrospective cohort study of cases notified with pulmonary TB. Patient Median delay = 34.5 to 54 days	Retrospective cohort study	Shorter delay was found in those with PTB, young patients, and those with smear+ TB, presenting at the A&E and born in high prevalence country. The study has not highlighted any particular patients' factor contributed to the delay. The study found capacity to deliver TB services by health care services I part contributed to total delay. HC related delay was 29.5 days.	Weaknesses associated with the analysis based on survey of clinicians' accounts.
46. Storla et al 2008	Systematic Review of evidence on delay in diagnosis and treatment	58 studies addressing delay in accessing and treatment for TB.	Systematic Review of 58 studies in different socio-economic settings employing various methods of researches.	From review of studies, several factors found to contribute to deal in help-seeking: HIV, chronic cough/other lung diseases, low access (geographical or socio/psychological barriers), initial contact with low level health care facility, private practitioner or traditional healer; old age; female-sex; alcoholism; and substance abuse, history of immigration, low educational level, low awareness of TB, incomprehensive beliefs, self treatment, and stigma.	The systematic review highlights the core barriers to diagnosis and treatment related to vicious cycle of repeated visits and ineffective treatment and delay after specific diagnosis is short and reasonable.
47					
48. Npang et al. 2007	To identify beliefs and popular perceptions on cough and determine health-seeking behaviour.	Rwanda Qualitative study Twenty-one key informants were interviewed:	Eight focus group discussions, 21 key informant interviews and 12 illness narratives were conducted between May and June 2004.	There is wide use of herbal treatment for chronic cough in Rwanda. TB symptoms are often mistaken for the acquired immune-deficiency syndrome (AIDS). Three health seeking end points emerge for chronic cough: home care, health facility and the traditional healer. Healers in some areas, however, believe TB due to witchcraft can only be treated traditionally.	
49. Dos Santos et al 2005	This study investigates factors associated with total delay in treatment of tuberculosis.	Recife Brazil Interview Cohort of 1,105 PTb pts interviews	Exposures studied: age and sex), alcohol consumption, social factors (employment status, marital status, literacy; numbers of dwellers, income, contact with cases of tuberculosis (previous tuberculosis treatment, cough, weight loss, HIV co-infection, and haemoptysis), treatment is located, and access to health services (number of health units attended and location	Of 1105 patients, 62% had a delay of longer than 60 days. Age, sex, alcoholism and difficulty of access were not associated with delays, but associations were found in the case of unemployment, having given up smoking, having lost weight and being treated in two of the six districts. Associations were investigated using univariate and multivariable analysis and the population attributable fraction was estimated.	The study highlights that unemployment, having given up smoking, lost weight, being treated in two of the six districts. In two of the six districts delay was significantly higher There may be confounders associated with these areas that were not clarified
50. Asbroek et al. 2008	To examine patients' pathways to TB diagnosis and treatment employing semi-structured	Nepal one of five selected DOTS (sub-) centres in Nawalparasi on a day that interviews were	In semi-structured interviews, respondents were invited to tell their story of how they first perceived their complaints, sought treatment, and eventually	Patient routes often started in the medical shop and led via intricate routes with multiple providers to facilities. Besides known patients factors (such as severity of complaints, the ability to pay for services, availability of services and peer support for choosing a provider) specific health services factors were also identified. Perceived quality,	The study highlights pathways to tuberculosis treatment are typified by self referral. After suspected referral for diagnosis and treatment is

Author / Year	Aim	Setting / Sample	Method	Findings	Usefulness
	interviews with 26 hospitalized patients on treatment.	held. We interviewed 26 tuberculosis patients.	ended up in the tuberculosis treatment program. We asked respondents about their route through the health care system and the reasons for this route. A topic list was used to semi-structure the interviews.	costs and service level of a provider, and lack of provider initiated referral. Self referral because of waned trust in the provider was very common. Patients reported that the decision to change provider was usually taken by the patient themselves, supported by suggestions of their peers. Referral by providers seemingly was not based on the provider's perception of his own competence, the symptoms presented by the patient, or the lack of treatment results.	prompt.
51. Sagbakken et al. 2010	to explore experiences of being diagnosed with tuberculosis (TB) with a view to factors associated with diagnostic delay.	Norway in the city of Oslo county of Akershus in purposeful sample of 10 male and 12 female TB patients who originated from either Somalia or Ethiopia	A semi-structured interview guide covered five major themes: (a) symptom identification and health related behaviour; (b) experiences related to the diagnostic process; (c) information and understanding of the disease; (d) social support factors; and (e) perceptions and experiences as a TB patient in the context of	One-third of the participants reported less than 2 months from onset of symptoms to treatment were initiated, presenting with typical TB symptoms, or being screened for TB at arrival. Two-thirds of the participants told about extensive diagnostic processes. Participants experienced that the diagnostic process in the health services could endure for months, even years. The diagnosis could be difficult to confirm, but health professionals appeared to have difficulties with associating their symptoms with TB. This resulted in delays in initiating diagnostic tests for TB, especially in cases of extra-pulmonary TB.	The study highlights that an increased awareness among health professionals about typical and atypical symptoms of TB, aspects of the patient's history, and being aware and sensitive to patients' own interpretation of symptoms may reduce diagnostic delay in the health services.
52. Squire et al. 2005	To describe pathways to diagnosis and treatment and explore factors	5 patients, and the carers/families of 14 patients died of TB.	Retrospective follow up of lost smear + Tb cases	Useful	Useful
53. Marais 2006	The investigation focused on structural influences determined at, and operating across, community and sector level within the local context.	London Westminster A multi-method Community-based Participatory Research design involving 282 non TB community members. Involving 30 TB patients	FG, Semi Structured interviews with 11 previous TB patients Questionnaire survey interview (SI) = 5 Semi-structured interview (SSI) 11 and community consultation =14 Quantitative and Qualitative analysis	*Referral delays:* difficulties in obtaining access to a health specialist or the local hospital owing to a reluctance on the part of their GP to arrange referrals. Some reported having been refused referrals and screening by GPs because, as asylum seekers or awaiting failed asylum seeker status, they were only temporarily registered. *Delays in receiving treatment for tuberculosis:* a combination of individual and healthcare system delays. The findings suggest several weeks of ineffective antibiotic therapy coupled with GP failure to investigate for TB ranging from several weeks to 6 months, experiencing TB symptoms for 4 years before receiving appropriate medical care from his GP. Others demanded a referral to the local TB Clinic. In desperation, a few self referred. Ongoing reluctance to re-access their GP for health advice. They felt their GP lack of knowledge about TB and had little interest in, or understanding, of how the disease affected their lives, a breakdown of confidence and trust led to directly accessing the local TB Clinic, or the HIV Clinic.	The study highlights that patient and provider related delays based on the accounts of 11 patients on barriers to diagnosis and treatment.
54. Metcalf et al. 2007	To understand the process of diagnosing TB in UK primary care.	South-east Wales UK Interviews were conducted with 17 patients diagnosed with TB	Qualitative inductive study categories as were gathered until categories were saturated. Categories were merged into themes categories of data; data were coded into these. Data analysed thematically.	Both GPs and patients reported atypical presentations, and then the diagnostic and referral net was appropriately widened identified barriers to prompt diagnosis included atypical presentations and low clinical suspicion of TB, lack of continuity of care, workload demands that limit time with patients, and suboptimal clinician–patient communication. GPs recognised the need for improved education among health professionals.	The study highlights that GPs' and patients' accounts about the process of diagnosing TB. Not clarified the extent of factors related to either patient or providers

facilitated by NUD*IST software

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56. Watkins et al 2004	aimed to explore factors affecting treatment seeking for TB-related symptoms	**Indonesia** Bali I southern province 5 TB pts. 6 TB suspects non randomly selected	**In-depth interviews qualitative** content analysis coding data from each interview and subsequent grouping of these codes to represent main themes.	Lack of awareness, RX barriers/default, stigma fear. Participants described little communication with treatment providers. Treatments were inappropriate, limited amounts of medications, and varying medications. Symptomatic treatments over an extended period without diagnosis. Treatments services delayed, Default from treatment were often associated with a poor understanding of the treatment and cost	The five interviewees account highlighted factors associated with the quality of the providers care.
57. Togby et al. 2006	This study examined factors associated with patient delay, and health system delay.	Fast Sikkim India into 2 Tuberculosis units and 4 microscopy centres in **East Sikkim, India** .	**cross-sectional survey (CSS)**323 TB pts. patients (median age 30 years, men: 190) a pretested structured interview schedule	Patient delay >30 days was reported by 17% and health system delay >7 days by 49% of the participants. Patient delay was associated with self-medication (OR 2.28, 95% CI: 1.0–5.18), choice of government doctors as first contact (OR 2.76, 95% CI: 1.15–6.62), use of traditional healers (OR 2.18, 95% CI:1.03–4.61) and cost of treatment ≥Rs 400 compared with <Rs 100 (OR 2.52, 95% CI: 1.17–5.38). Important predictors of health system delays were first contact with private doctors (OR 33.1, 95% CI: 13.44–81.49) and cost of treatment (OR 2.5; 95% CI: 1.22–5.128).	The study highlights that self-medication; choice of traditional healers and private doctors and cost of RX. Although effort was made to reduce minimise recall bias by interviewing the patients at the time they reported analysis was based on demographical factors limited on health facilities experiences.
58. Van der Werf et al 2006	To assess the magnitude of patient delay and evaluate risk factors for delay.	**Ukraine** In Kiev city Interviews and medical records 190 newly DX TB pts.	The median time between the start of symptoms and the first visit to a health care provider (patient delay) was 30.0 days Socio-demographic factors and symptoms noticed before health care seeking Statistical analysis using univariate and multivariate analysis.	Individuals reporting unemployment, cough or loss of weight before seeking health care had a longer patient delay. The same applies to individuals with the risk factors homelessness, joblessness or alcohol abuse. The main reasons for delay among those who presented late were 'thought symptoms would go away' and 'symptoms not considered serious'. In this study, we assess the magnitude of patient delay and the number of health care facilities visited before the start of TB treatment.	The study highlights that Homelessness; unemployment and alcohol abuse. Although, the mortality rate among TB patients is high it is not clear from the data
59. Peheme et al 2007	To estimate health system delays (HSD) in the diagnosis of pulmonary tuberculosis (PTB)	**Estonia** Tartu, Valga, Võru, Viljandi, Põlva and Jõgeva counties in Southern during 2002–2003 **Interviews**	interviews. Data sources: smear negativity; absence of cough. Chest X-ray result; age; medical assistance first sought, the patients first contact emergency department or non-chest specialist.	The factors significantly associated with HSD greater than the median (19 days) and the 75th percentile (40 days) were smear negativity, absence of cough among symptoms, absence of chest X-ray during the first visit and age >60 years. A significantly shorter HSD was determined in non-Estonians and unemployed patients. HSD was not associated with the specialty of the doctor first contacted by the patient.	
60. Okur et al 2006	The present study investigated patterns and reasons for delays among patients with smear-positive pulmonary tuberculosis in Turkey.	**Turkey** Istanbul Heybeliada Center for Chest Disease and Thoracic Surgery 151 newly DX TB pts.	**Interviews** The mean time from the onset of symptoms to the first visit to a physician; the mean referral delay; the mean delay in diagnosis; and the mean delay in treatment initiation.	There was a delay in consulting a physician by 49% of patients. A low index of suspicion for tuberculosis on the part of the physician and healthcare system and laboratory delays were the most common reasons for delays in diagnosis.	The study highlights that most common reasons for a doctor's delay were a low index of suspicion laboratory delays and the distance to a hospital.

Author/Year	Objective	Setting/Sample	Study design	Results	Conclusion
61. Sadiq et al. 2001	To determine the health care seeking behaviour of TB patients in seeking care and health care providers for delivering care.	**Rawalpindi** Rawalpindi(specialized TB clinic). 160 newly diagnosed TB pts.	Cross Sectional Study – interviews	Most patients consulted within three weeks (77%) and delay was primary factor prior to their consulting TB Center, 96% patients had already reported to a health care provider, i.e., to first, second or third health care providers. Of 154 patients, 48 were diagnosed as TB and only 29 (19%) of them received anti tuberculosis treatment. Most of the patients 118 (77%) consulted the health care provider within three weeks time.	Delay is more on part of health care providers than on patients. Proper implementation of collaboration and continuing education of health care guidelines
62 Jean –Ralph et al. 2001	To clarify the patterns of high index of suspicion and identify predictors of 30-day mortality	Pats. admitted f respiratory failure 99 TB pts	**Retrospective case analysis.** All patients admitted with pulmonary TB their clinical and laboratory data at admission and events within 48 h of admission were collected. Predictors of 30-day mortality were identified by univariate and multivariate analysis.	All 99 patients were admitted for acute respiratory failure, some also with shock (20). neurologic disorders (18) or acute renal failure (10). Four factors independently predicted mortality: a time from symptom onset to treatment of more than 1 month (OR, 3.49; CI, 1.20-10.20), the number of organ failures (OR, 3.15; CI, 1.76-5.76), a serum albumin level above 20 g/l (OR, 3.96; CI, 1.04-15.10), and a larger number of lobes involved on chest radiograph (OR, 1.83; CI, 1.12-2.98).	The study highlights that delay in seeking medical help and low index suspicion likely to contribute to high mortality rate of TB patients.
63. Gershon et al. 2008	To estimate delays in TB treatment in a Canadian, multicultural population and to examine factors associated with longer time to treatment.	Ontario Canada TB surveillance data reported by health care providers	1753 TB patients	Data from 1753 TB patients (76% of eligible patients) were analyzed. Median time to treatment was 62 days (interquartile range 31 to 114 days). Time periods longer than the median time to treatment were independently associated with middle-aged patients (OR 1.54, 95% CI 1.21 to 1.98), foreign-born patients who had lived in Canada for more than 10 years (OR 1.47, 95% CI 1.02 to 2.12), patients with non pulmonary disease (OR 1.57, 95% CI 1.28 to 1.92) and patients managed within certain health districts.	Those who were middle aged, foreign-born and lived in Canada for more than 10 years, who had non pulmonary TB, and who were treated within certain health units were more likely to experience a longer time to treatment.
64 Cummings et al. 1998	To determine treatment outcomes (completed, defaulted, died, other) for 131 (89%) of these 147 patients	TB patients in California 2,576 adult TB pts.	Cohort study	Diagnosed TB in state prisons; abuse drugs; homelessness; being in congregate prisons and jails... Patients who moved defaulted more often than patients who did not move. Including these patients' treatment outcomes increased the known number of defaulters by 30%, from 141 to 183 persons. Diagnosis of TB in a state prison. Patients who moved or defaulted were more likely to abuse drugs or alcohol, to be homeless or to be associated with congregate settings such as jails and prisons emerged as the strongest risk factor for defaulting from treatment.	The study highlights the importance of ensuring complete treatment for TB patients who move;
65 Goulb et al. 2005	To assess the implications of antibiotic treatment pneumonia (CAP) on delays in the diagnosis of TB, and to assess the frequency with which chest radiographs (CXRs) were utilized before a diagnosis	USA DH Maryland 158 people of which 86 were TB patients All culture-confirmed TB patients reported Patients were interviewed concerning their interactions with the health care system when seeking care for their TB symptoms.	Nested case-control study 85 cases and 73 controls	Of 54 patients who did not have a CXR at their first health care visit, 41 (79%) received empiric antibiotics, compared to 44/105 (42%) who had a CXR (P < 0.01). Only 31/54 (57%) patients initially diagnosed with CAP had a CXR at the time of diagnosis. The researchers found that patients who received antibiotics prior to TB diagnosis had a diagnostic delay that was twice as long as that of patients who did not receive antibiotics. Moreover, the delay was similar regardless of the antibiotic class prescribed. Every effort was made to review all relevant records, diagnostic tests and physician notes and to compare these with patient interviews.	More widespread use of CXR reduces diagnosis delay and unnecessary use of ABt.

# / Author	Objective	Setting / Population	Methods	Findings
66. Needham et al. 2002	To clarify if these factors associated with patients' diagnostic delay	**Zambia.** Urban Zambia Chest Clinic in Lusaka, 202 adult PTb patients involved	Semi – structured interviews In-depth interviews were performed with consenting patients focusing on socio-economic and care seeking data, relevant variables affecting diagnostic delay were identified through literature review	Financial constraints; on average 6.7 contacts prior diagnosis; travel at distance are main barriers to health acre seeking. Being female sex, lower education, more than six instances of health-seeking encounters, outpatient diagnosis of tuberculosis, and visiting a private doctor or traditional healer.	The study highlights that female sex, lower education, more than six instances of health-seeking encounters, outpatient diagnosis of tuberculosis, and visiting a private doctor or traditional healer.
67. HO- M-J et al 2004	To investigate the health-seeking behaviour patterns of Chinese immigrant patients enrolled in the directly observed therapy (DOT) program	DOT) program in **New York City**, and to suggest service provision strategies. 60 pts. Only 22 diagnosed at HS	**A semi-structured, open-ended interview** was then used to fill in the gaps in their illness narrative. The interview questions were modified from Kleinman's explanatory models of illness. Medical records and epidemiological data were also utilized to supplement data descriptive data, and were analyzed statistically. Qualitative data was by coding data closely using grounded theory approach 'develop' theoretical	38 symptomatic patients sought care from Chinatown physicians, including traditional Chinese practitioners, fewest referrals to the DOT program. An analysis of their illness narrative reveals that their reason for provider selection is convenience.	
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71. Diez et al. 2005	To investigates HSD and associated factors in culture-confirmed TB patients.	**Spain** In 13 (out of the 17) of Spain's Autonomous Regions 5,184 records of CC TB patients	**Clinical Records** Hospitalized culture confirmed TB patients Dates of first medical visit and initiation of treatment were obtained from the clinical record in the visit that lead to diagnosis and the time lag between these two dates was calculated in days. Analysis: Using logistic regression with two different cut-off points to define HSD (median and 75th percentile), adjusted odds ratios were used to estimate the association between HSD and different variables.	HSD significantly greater than the median was associated with: age .44 years, past or present intravenous drug use, diagnosis at a primary care centre, prior preventive therapy, positive histology, request for drug-sensitivity testing, presence of silicosis or neoplasia in addition to TB, presence of non-TB related symptoms, and gastrointestinal site.	The study highlights that in some groups of TB patients whose treatment is unduly delayed. Association with female gender and age 44 years emerged the highest delayed by health service

Study	Objective	Setting / Population	Study design / Methods	Results	Conclusions
72. Gagliotti et al 2006	To quantify patient and health care delays in the treatment of pulmonary TB and association between migration status and delay.	**Italy**, Emilia-Romagna. Italy **Emilia-Romagna region**, The study population included 271 patients, 142 (52.4%) Italian-born and 129 (47.6%) migrant, with a mean age of 47.6 years (median 40 years).	Prospective follow up. **Data sources: local health authority officer in charge of surveillance data.**	Migration status; Italian patients had longest HSD (60 median days) Where as recent migrants <3 years the longest pt patient delay (16 median days). Migration status was independently associated with both patient and health care delay, although the direction of association changed according to which delay was considered.	The study highlights that long health care delay was higher for patients consulted health providers other than a chest physician or emergency services.
73. Gomez et al. 2003	To study symptomatic pulmonary TB diagnostic delay.	**Spain** 287 Symptomatic new TB patients in	Prospective study – **structured interviews** with pts and families The main variables analyzed were patient's delay (PD), doctor's delay (DD), diagnostic process delay (DPD), health care system delay (HCSD) and total delay between the onset of symptoms and start of treatment (TD). Univariate and multivariate statistical analyses were performed for each component of delay	Patients are responsible for 50% of excess delay in diagnosing symptomatic PTB. Patients in the health care system experienced diagnostic delays over 60 days in 18.5% of cases, doctors being responsible for 75% of the diagnostic delay attributable to the system.	Findings are limited to quantifying delay rate than identifying underlying barriers and facilitators of pathways
74. Macg et al 2004	To assess medical costs incurred by patients and delay between first contact and sputum test for acid-fast bacilli (AFB)	**Nicaragua** in three areas of Nicaragua. 252 TB suspects	Interviews The data collected included the patient's socioeconomic and health status, medical costs incurred by the patient, health service delays, care provider utilisation and referral patterns. The questionnaire was designed by the authors and pre-tested in two health centres of the capital, Managua.	Factors associated with delays more than one type of care giver and 35% used private practitioners. Spent more than 1 month of the country's median income per inhabitant on medical care between the first visit to a care provider and the first sputum examination. Furthermore, more than 3 months elapsed on that part of the care pathway for 30%, 17% and 3% of interviewees in Matagalpa, El Viejo and Carazo, respectively. Poorly performing and unregulated private care and delayed in reaching diagnostic facilities for TB.	The results of this study illustrate the often complex care pathways followed by TB suspects before they are sent to a laboratory for AFB sputum examination. *Study examined cost and health care incurred by TB suspects in their pathways.*
75. Meintjes et al. 2008	To describe patient and provider delay in the diagnosis of TB in patients and to determine the risk factors.	**South Africa** Secondary care in Cap Town. 125 patients of these 104 pts were diagnosed	A Cross Sectional Survey – interviews using Structured Questionnaire Data regarding TB diagnosis and outcomes were obtained from the medical records. quantified diagnostic delay, associated factors, and consequences	Factors independently associated with longer patient delay were male gender, cough and first health care visit being to public sector clinic (compared with private general practitioner). Patient delay ≥ 14 days was associated with increased need for transfer to a TB hospital. Provider delay ≥ 30 days was associated with increased mortality. Being male, cough and first contact public sector clinic; increased need for transfer to a TB hospital	The study highlights factors linked to patients but interviews could not adequately explore health system issues such as referral pathways and investigation practices.

Author	Objective	Setting	Design	Findings	Comments
76. Hui-Ping et al 2009	The tuberculosis reporting enquiry system	Taiwan China 114, 827 cases reported of these 22,067 were diagnosed	Retrospective enquiry of cases notified in **TB Surveillance data** Multiple logistic regression analysis was applied to analyze the risk factors associated with these delays.	The main factors associated with diagnosis delay included age, reporting year, living with family and a positive sputum culture, increased age, an aboriginal ethnic background, a positive sputum culture and diagnosis at a nonmedical centre. It is interesting to note that a much stricter definition of delay a period of longer than 9 days was defined as a *diagnosis delay* and a period of longer than 2 days as a *treatment delay*.	Greater age and a positive sputum culture significantly increase both diagnosis and treatment delays; treatment delay. Information about access to professional care to aboriginal ethnic groups would have been useful not addressed.
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79. Godfrey-Faussett et al 2002	To determine risk factors associated with delay seeking care among	Zambia Urban health centre in Lusaka, Chipata and Kanyama 427 TB patients interviewed	A Cross section Survey interviews with TB patients and result discussed with policy makers and professionals Indicators developed to generate questions symptoms started, about their cough, why they had chosen clinic and not sooner, knowledge about, stigma and TB.	Delay was associated with older age, severe underlying illness, poor perception of the health services, distance from the clinic and prior attendance at a private clinic. No relationship between delay and knowledge about tuberculosis, nor with education, socio-economic level or gender and stigmatising attitude.	The study highlights that *delay was associated with knowledge and education. Findings are limited to assessing patients factors rather than providers related factors*
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81. Lawn et al. 1998	To determine the factors affecting the delay from the onset of symptoms until the initiation of treatment.	Ghana Komfo Ankye hospital, Kumasi A newly diagnosed 100smear +ve TB patients	Design: A retrospective **questionnaire survey** of newly diagnosed smear-positive pulmonary tuberculosis. Analysis involved case notes and referral letters	Doctor delay was significantly increased in females, rural patients, and among those needing hospital admissions. Increased doctor delay was strongly correlated with rates of failure to perform sputum microscopy ($r = 0.99$), low rates of diagnosis, and was seen particularly among private practitioners and rural government institutions.	The study highlights that HSD is increased in female patients, rural residence and needing hospital admission... failure to perform sputum microscopy, low rates of diagnosis among private practitioners and low level rural health institutions.
82. Huong et al. 2007	To assesses the patient, health care provider and total delay in diagnosis and treatment of smear-positive pulmonary tuberculosis patients.	Vietnam In randomized 20 urban, 20 remote and 30 rural districts 2, 093 smear +ve PTb pts	A Cross Sectional Study interview using pre-coded structured questionnaire Univariate and multivariate analysis of risk factors to delay Patients were interviewed using a pre-coded structured questionnaire (age, sex, ethnicity, education and distance from the patient's house to the first health care provider); onset of cough and first contact with health care provider; date of diagnosis; starting date of treatment.	Independent risk factors ($p < 0.05$) for long total delay were female sex, middle age, remote setting, residence in the northern or central area, and initial visit to the private sector. For long patient delay (≥ 6 weeks) this was female sex, belonging to an ethnic minority, and living at > 5 km distance from a health facility or in the northern area. For long health care delay (≥ 6 weeks) this was urban setting, residence in the central area and initial visit to a communal health post, TB hospital or the private sector.	*Findings are specifically focused on variables of researchers interest and have not examined factors from patients' own experiences*

Study	Aim	Setting / Sample	Method	Findings	Comments
83. Aye et al. 2010	The study investigated extent and determinants of patient and health system delays for TB.	Twelve health districts in Tajikistan 204 Tb patients interviewed	A cohort of patients interviewed using questionnaire Cox proportional hazards models using eight predictor variables, including characteristics of health services delivery, were built to identify determinants of patient and health system delays.	The type of facility, where patients made their first contact with the health system, was the main determinant of health system delay ($p < 0.00005$). Those who first presented to peripheral primary care facilities also had relatively long delays.	The study highlights that the type of first contact facility – health care in Russia, and peripheral primary care facilities had relatively longer delays.
84. Harper et al 2003	To investigate the contribution of non-biological factors for effective diagnosis and treatment	TB patients, the community, health care providers, donors and policy makers: FG discussions, (n=40) PO and non PO, case histories. Semi structured interviews	Multi method design In-depth interviews Participants observations, case histories were also used with those completed treatment, defaulted, those in whom treatment failed including families.	Gender, urban/rural residence, recourse of traditional healers, knowledge about TB, migration and socio-economic factors. Researchers interested to investigate seven main areas : gender, urban/rural residence, role of traditional healers, adherence to stated health care policy, migration, socio-economic factors, knowledge of TB	*The study is unable to look into the health service related factors in particular*
85. Sreeramareddy et al 2009	To summarize the data on delays in diagnosis of tuberculosis.	**Systematic Reviews of** fifty-two studies qualified for review.	Search terms: indices of four major tuberculosis journals were hand-searched. Reference lists, review articles and text book chapters' methodological quality assessed.	Both patient delay and health system delay in low income countries (31.7 days and 28.5 days) were similar to those reported in high income countries (25.8 days and 21.5 days). Only studies carried out on smear/culture-positive tuberculosis patients and reporting about total, patient and healthcare system delays were included.	Findings are limited to measured delay by categories of time length rather than factors contributory to delay
86. Smith et al 2006	To examine how frequently patients with TB attended the local A&E led to a diagnosis of TB being made	**UK. London** 130 notifications of TB at University College London Hospitals. Of A&E attendees,	**Surveillance data from A&E records** For each patient with TB the A&E department records were examined for the 6 month period before the date of diagnosis.	Thirty six of the 41 (88%) had no access to a general practitioner; the majority self-referred to A&E. Almost one third of patients with TB attended the A&E department in the 6 months prior to diagnosis. The diagnosis of TB was missed in 10/41 A&E attendees (24.3%). 69% of patients in whom TB was subsequently found required admission to hospital compared with an overall figure of 6.7% of all A&E attendances during this period. The diagnosis of TB was made as a direct result of the A&E attendance in three quarters of patients. Missed diagnosis include failure to suspect TB, presenting symptoms not typical of TB, patients may not have had TB at the time of their A&E presentation	The study highlights that one quarter of patients sought care from the A&E were missed diagnosis. Clinicians failure to detect TB and patients may have presented symptoms non typical of TB as possible reasons.

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Amongst Abstracts Reviewed the full-texts of two studies below were non-English. (see some data extracted from their Abstratcts)

Authors	Study aims	Settings, Participants and Samples	Method/Framework and Analysis	Outcomes / Findings	Strengths and Weaknesses
1.Alvarez-Gordillo et al 2000	To identify health perceptions and practices and non-adherence to therapy among tuberculosis patients	**Mexico** Central highlands 62 patients with TB	**Group interviews** 11 groups with 62 tuberculosis patients	Perceived causes of tuberculosis included contagion via food utensils, excess work, malnutrition, and cold, economic crisis for both the patients and their family, social stigma imposed by the disease, patients perceived a negative impact on their personal life, family, work, and community. Inadequate patient-doctor relationship resulted in diagnostic delay	The study highlights that misconception about TB: social stigma of disease *The findings from this is limited to identify factors form patients on health care seeking practices (experiences)*
Full Article non-English	(Abstract)	(Abstract)	(Abstract)	(Abstract)	**Excluded as full – text article was non-English**
2. Gomez et al. 2003	To study symptomatic pulmonary TB diagnostic delay	**Spain** 287 Symptomatic new TB patients in	Prospective study – **structured interviews** with pts and families The main variables analyzed were patient's delay (PD), doctor's delay (DD), diagnostic process delay (DPD), health care system delay (HCSD) and total delay between the onset of symptoms and start of treatment (TD). Univariate and multivariate statistical analyses were performed for each component of delay	Patients are responsible for 50% of excess delay in diagnosing symptomatic PTB. Patients in the health care system experienced diagnostic delays over 60 days in 18.5% of cases, doctors being responsible for 75% of the diagnostic delay attributable to the system.	Findings are limited to quantifying delay rater than identifying underlying barriers and facilitators of pathways
Full Article in Spanish	(Abstract)	(Abstract)	(Abstract)	(Abstract)	**Excluded as full – text article was non-English**