

BMJ Open How can the priorities of older, frail patients and their carers be used to inform policy and practice at the end of life? Insights from qualitative research across multiple settings

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ABSTRACT

Objectives The paper reports on experiences from older patients and their carers of current provision of end-of-life care in England. It draws on data from a study that sought to explore the extent to which national policy for end-of-life care in England was aligned with the aspirations of stakeholders. Specifically, the study explored the balance between clinical healthcare vs social and relational care asking how this was aligned to patient priorities at this time of life. Here, we examine the extent to which the patient voice is attended to when health and social care services are delivered to older people and consider how the experiences of patients and carers could be used to improve outcomes.

Design The work draws on data collected as part of a realist informed study using a case study approach to gather data.

Setting Clinical Commissioning Groups were used as the boundaries of the three case studies and within these geographical areas data was collected in hospitals, care homes, hospices and patient homes.

Participants This paper reports on in-depth interviews conducted with 21 patients at the end of life and 22 relatives/carers (n=43).

Results While the medical care patients received was generally praised, it was reported that relational care, particularly in respect to adult social care received at home, was fragmented and of varying quality. Relational and social support were key to the patient and carer experience yet appeared to be hard to access.

Conclusion The work highlights the misalignment between the availability of different types of care at the end of life and patient priorities. More attention should be paid to the voice of older patients and their carers, drawing on their experiences to influence the way policy is translated into practice.

OBJECTIVES

Globally, the average length of life over the last two centuries has shown a dramatic increase. In England for example, while women had an average life expectancy (LE) of 42.3 years in 1841, this had risen to 83.6

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The case study methodology adopted sought to achieve depth of understanding over generalisability.
- ⇒ The sample was drawn from inner and outer London; an area with unique demographics which distinguish it from the rest of England, particularly in relation to its greater diversity in ethnic composition.
- ⇒ The realist informed 'interviewer-led technique' may not always be appropriate and was adapted in the course of the study in response to the needs of older, frail, patients facing the end of life and their carers.

years in 2019.¹ This rising LE, seen as an indicator of a thriving economy and an advanced health system, is celebrated by politicians.² Yet, increases in number of years lived are matched by an increase in the number of co-morbidities suffered. Healthy life expectancy is not keeping pace with LE and we suffer increasing chronic ill health as we age. In 2018–2020, a woman in England could expect to live 23% of their life (19.3 years) in 'not good' health.¹ These figures are mediated by inequality with those in the least deprived areas living 84.6% of their time in 'good health' compared with only 71.1% of those in the most deprived areas.¹ This data does not reveal the broad spectrum of largely unknown suffering and the point at which the individual determines the quality of their life has fallen so low they would prefer no longer to be alive is blurred by a complex maze of ethical, social and cultural dilemmas. What is clearer is that as individual health deteriorates and quality of life begins to fall, the need for social care rises, as does the burden on social care providers. This paper explores some of the pressures emerging from this contextual backdrop in health and social care and asks how the perspective and priorities of older

people, at the end of life (EoL), can be used to improve outcomes.

In England, despite the growing need for social care, the health and care systems continue to privilege clinical care. At the root of the fragmentation long observed in the health and social care systems in England and significantly impacting on how services are run, is the way funding has historically been distributed across health and social care. Healthcare spending accounts for £1 in every £5 spent by the government—amounting to more than £150bn across the UK in 2019–2020, while public spending on adult social care is around £18bn.³ Moreover, social care funding in England over the last decade has fallen in real terms from a peak in 2010–2011, with a decrease between 2010 and 2019 of 4.9%.⁴ Additional pressures on the social care system due to the ageing population have meant that access to services has been substantially reduced.³ These figures may inform a range of outcomes noted during the pandemic. The unprecedented numbers of deaths in care homes between 2019 and 2021 fuelled the suspicion that securing COVID-19 testing and personal protective equipment (PPE) in the care home sector was considered less of a priority than provision across the NHS.⁵ Commentators speculate about how the gulf between the ‘two cultures’ of the NHS on the one hand and social care on the other has become increasingly polarised.⁵

The way EoL care is delivered in England is often far removed from the aspiration to provide a joined up, seamless service along the patient pathway.⁶ Confusion is voiced over how services are funded, commissioned and regulated. While hospital services are funded by the state, through the National Health Service, a large part of hospice funding is provided by charities⁷ and other services, providing support for frail older people, are supported by local authorities or charitable enterprises. Putting exact figures on clinical vs social care spending is notoriously hard to do and priorities differ by region.⁸ Older people may find it easier to access medication, investigations and clinical interventions rather than support for basic health and care needs. Furthermore, psychological health needs are often overlooked in older age, despite depression being the most common health problem in those over the age of 65.⁹

Interventions at the EoL are underinvestigated due, in part, to the considerable methodological and ethical challenges, meaning that patient experiences often go unheard—this research therefore fills an important gap in literature.¹⁰ This article draws on a research project which explored the national implementation of EoL policy, in which a wide range of stakeholders were interviewed to explore alignment of policy priorities in each group, and the broader study is reported elsewhere.^{6 11} The paper focusses on the voice of older people aged 75+ years, identified by clinicians as being at the EoL, and their carers, to reflect on how to align current system pressures with patient wishes. The term carer is used here to describe those who took on an unpaid role providing

support to someone at the EoL, in the vast majority of cases they were relatives, usually a child or spouse.

METHOD

Design

The broader study from which this paper is drawn followed a theory-driven, realist evaluation (RE) methodology and comprised a scoping study followed by three case studies conducted across London Clinical Commissioning Groups (CCGs) between November 2018 and November 2019. To improve reliability and validity, a standardised procedure was followed using RAMESES II, a 20-point advisory check list to be followed in REs.¹² In addition, the Consolidated criteria for Reporting Qualitative research (COREQ) checklist was used to check for completeness and transparency of the study (see online supplemental Annex 1). RE was considered an appropriate method of enquiry to maximise learning within the complex world of national policy and its application across institutional, organisational and individual barriers and boundaries. Its recognition of the complexity of the social world and acceptance that causality is often not linear, fitted well with the multi-layered nature of this enquiry. The case study approach adopted allowed for an in-depth study of a complex intervention in the context in which it was implemented.

Patient and public involvement

Patient and public involvement was facilitated through the ‘Opening Doors to Research Group’ (ODGR), based in Kent and made up of 25 members of the public who advised on the creation of research tools. Following the completion of the case studies, of which the voice of patients and carers formed a significant part, we returned to the ODRG to ‘sense test’ some of the early analysis and discussed theory development. Patient participants were at the EoL and understood that study findings would not be directly fed back to them.

Setting

Interviews were conducted across multiple settings including patient homes, care homes, hospice and hospital.

Local commissioning within the NHS in England was, at the time of the study, the responsibility of CCGs; these were therefore chosen to represent the most tangible governance structure through which to organise case studies looking at local implementation of EoL care. The final decisions about site selection were guided both by a desire to choose sites that would provide contrasting characteristics, pragmatism and logistics.

A total of 98 in-depth interviews were conducted across the different sites with a sample made up of clinicians, commissioners, service managers, patients and relatives. Given that this paper seeks to privilege the patient voice, we focus here on the 43 interviews conducted with patients (n=21) and relatives/carers (n=22). Online

Table 1 Inclusion and exclusion criteria for patient recruitment

Inclusion	Exclusion
Aged 75 and over	Recognised cognitive impairment which means they cannot engage in lucid conversation
Identified by clinician as being likely to die within the next 12 months	Non-English speaking—unless an interpreter in the form of a family or friend can be identified
Able to make informed decision about participation and enter into discussion	Those very close to the EoL, that is, expected to die within the next few days
If a carer/relative is identified as a primary source of mental/emotional support, they will also be approached for consent to participate	Patient who has not had a formal conversation with their clinician about the EoL.
Sample should represent a mix of one or more different conditions including (eg, cancer, coronary heart disease, frailty)	
Sample should represent experience of a range of community and acute services	
EoL, end of life.	

supplemental Annex 2 shows the breakdown of patients and carers across the three case study sites and provides data on their age, ethnicity, method of recruitment and place of interview.

Participants

Patients interviewed in this study either had advanced, progressive and incurable illnesses or were suffering extreme frailty and a range of comorbidities. Specific criteria are outlined in [table 1](#).

Recruitment

The sample of patients and carers was selected purposefully, supported by clinicians involved in their care with whom contact was made through EoL networks or care home managers. Patients were provided with written and oral information by the clinician and those happy to participate were followed up by the researcher who completed full written consent. Carers (usually relatives) were contacted in the same way through patients and/or clinicians. Interviews were conducted across a range of settings (home: 21, care homes: 6, hospice: 4, video/phone calls with relatives 12).

Interviews

Topic guides were used during the interviews, focusing on experiences of care and patient priorities at the EoL (see online supplemental Annex 3). Interviews lasted between 40 and 90 min and, with permission, were recorded for transcription purposes and pseudonymised. Interviews were continued until quotas were reached by which time saturation appeared to have been reached in most themes. It should however be noted that the concept of saturation does not necessarily fit well with realist thinking which posits that given the dynamic nature of the social world, where generative mechanisms have powers to change contexts, research outcomes will forever be in flux.¹³

Challenges which arose during the study, associated with the interview methods used, are reflected on in the

discussion section of this paper. No standard measures were used to assess psychological health—our interest being in the particular interpretation given to this area by patients themselves.

Analysis

Interview transcripts were initially read through for familiarisation and coded manually. Throughout this process, in line with theory development in RE methodology,¹⁴ notes were kept on emerging Context Mechanism Outcome configurations.⁶ Codes were then entered into NVivo¹⁵ and refined. The allocation of codes involved both induction (codes emerging from the data) and deduction (codes created in advance informed by the initial rough programme theory). The key stages of analysis were discussed with the project team and samples of coding were scrutinised across the team to ensure consistency of interpretation. Online supplemental Annex 4 provides illustrative quotes to show how codes were used to arrive at broader themes.

RESULTS

To preserve anonymity, the names of patients and carers have not been used and codes used to represent case study locations. Responses from patients and carers are considered under three major themes for which further illustrative quotes are provided in online supplemental annex 4 (tables 2a–4b). Under each theme, the perspectives of patients and their carers are considered separately.

i. Reflections on clinical and social care received

Patients

When reflecting on clinical care, patients tended to remark, not about the competency of the care itself (indeed this was generally taken for granted), but on the importance of having their experiences and opinions listened to;

For me good care is when they listen to me – not just to put me on a pill. I don't like taking tablets – they can do so many other things to you – some can make you better – but they always affect you in some other way and I don't like that. Some of the doctors – but not all – have been really good at taking the time to explain all these things to me. (CP6)

Transactional clinical care was highly regarded, and patients were generally satisfied that clinicians had access to and provided the best available treatment. In instances where patients knew their family doctor, they appreciated the level of individualised care received. A dignified bed bound, 82-year-old woman on a palliative care ward, spoke of the importance of being listened to and treated as a person who could still enjoy normal aspects of life rather than be defined entirely as a 'dying' person.

Yesterday when the doctor was here I said 'you know what – I'd love a Bacardi and Coke' ... 'Well' she said – 'there's no reason why you shouldn't have one here. They treat me as a human. (CP3)

Difficulties accessing care and the way different parts of the care system were joined together was frequently remarked on. Older patients reported how hard it was to get past receptionists to make appointments or to speak to people to receive results.

The receptionists say to me 'what is your emergency then' – can't it wait till another day? (AP2)

Examples of poor care experiences tended to relate to times when carers or clinicians were seen to lack empathy, treating them as 'cases' rather than people.

They'd all be discussing this that and the other – then they'd go off out the room – it was like they didn't notice ME. (AP2)

Relatives and unpaid carers

While relatives' experiences of the health and social care system usually mirrored those of the family members they were looking after, the issue of having to navigate fragmented, disjointed systems, through which the more vulnerable patients had to be guided, came to the fore. Particularly, when dealing with the frail elderly at home, the absence of a central point of contact, which could help to wrap services around the patient, was lamented. Those caring for relatives at the EoL reported the frustrations of having to re-tell the patient story from scratch to every new contact encountered.

Another significant theme for both patients and relatives facing the EoL at home was social care support. For many, the social care received was a lifeline, enabling them to keep their relative at home for longer than they would have otherwise managed—yet dissatisfaction was voiced in regard to communication and language issues and highly variable standards of care. Significant numbers reported the social care system as erratic and hard to manage. Both

patients and relatives struggled with: frequent changes in staff; carers often appearing much later or earlier than scheduled; issues with language and communication difficulties and lack of dignity relating to the most intimate aspects of care. Shortages of time to do required tasks meant that care was often experienced as transactional rather than relational.

There's nothing wrong with the carers – they're just not well trained – you don't know when they're coming and it's all so undignified – imagine having a young girl you don't know helping you in the shower. (CP8)

Relatives, who took the burden of responsibility for frail older patients at home, were sceptical that paid carers received appropriate levels of support and training to enable them to do a proper job. The strong consensus, reiterated time and again by all categories of respondent, was that the paid carer workforce was poorly recompensed, trained and supported, resulting in an unreliable workforce with low morale. While some paid carers provided high quality, compassionate care, the over-riding experience was negative, with patients and relatives lamenting a lack of choice and control. In multi-cultural areas, there were also challenges in finding carers who were appropriately matched in terms of language, beliefs and cultural preferences.

The anger felt by many at the poor status and level of resource assigned to adult social care and the lack of respect with which their loved ones were consequently treated was reflected in many of the stories recounted.

When my mum's care package went out to tender from continuing health care (CHC) – they just go for the lowest quote. If you did that for a sick child, and they were sending carers who were falling asleep because they are so exhausted – there would be an outcry. But that's fine for the elderly. Its fine if the carer signs something saying they've been there for an hour. (AC3)

Some respondents spoke strongly about the lack of respect and dignity observed.

There was one who didn't even say hi to my mum – there was no engagement at all. I said to her one day it would be nice if you could at least speak to your client. (AC10)

Perhaps, the biggest irritation voiced was the lack of control over who came and the frequent changes in, and turnover of, staff allocated by agencies. A small number of relatives got around this lack of control by managing a Personal Health Budget (PHB), effectively meaning they had more control over the selection and management of carers. This process however was reported to be far from transparent and very few carers were aware of the potential opportunities available.

To secure greater choice and continuity of carers, some families chose to spend their private income on

employing carers of their choice, though for many this was not an economically viable option.

ii. Challenges to good mental health

The way in which clinicians and service providers recognised, acknowledged and addressed mental health did not always meet perceived needs and was a common theme running through the interviews with patients and relatives/carers. Patients grappled with isolation and the fear of impending death, while for carers the responsibility and stress of their role appeared to impact on their well-being.

Patients

For patients, loneliness appeared to exacerbate depression, yet most of those interviewed were too frail to seek companionship. Some alluded to the feeling that pressure on resources meant corners were cut, particularly in non-clinical areas. Here, a care home resident bemoans his lack of company:

Well, you can see how many people there are around here – no one. No companions. It's like that all day long...Time goes so slow. Nothing happens! ...Time drags on and on and on. (BP4)

At times, the lack of purpose provoked even the most even-tempered to suggest to staff that they would benefit from increased levels of activity.

I don't do any of the group socials within the home because my oxygen lead only reaches to the top of the stairs. I think they've got a craft room downstairs – but I can't access that. I think it's something to do with the funding. After the first week I was here I kicked up a fuss – I asked if they had a project ...I'm knitting blanket squares.... They'll go to the jumble or Christmas fair or something. (CP3)

The ability of clinicians to know how to respond to low mood, within the complex range of competing physical challenges at the EoL, was mixed.

I phoned the doctor and said that I was more worried about her depressed mood than the leg. I said she's really, really low. It seemed to be a symptom of her diminishing ability. And to cut a long story short the doctor ended up saying ' – I'm sorry she's been so low'. But he never bothered to come and see her.... He sent a prescription electronically to the chemist. (AC1)

Impact on relative's mental health

The burden and responsibility of care took its toll on many of the relatives interviewed who spoke of their own issues around mental health, particularly those looking after patients suffering unpredictable conditions such as dementia and psychosis. For relatives who were reluctant to relinquish the care of family members, the responsibility of having to negotiate an often complex,

unresponsive and fragmented health and care system at times impacted negatively on their own well-being. A couple of carers/relatives stated that because of impenetrable bureaucracy and a constant sense that they were not getting what they felt entitled to, the best protective strategy was simply to disengage:

They will not offer it {help} to you and they don't listen to you. There's a great deal of patronising that goes on – and not really supporting you to carry out the role. I found all the promised support comes to nothing. It's better just to do it yourself. (AC3)

The experience of isolation and anxiety was evidenced in carers as well as patients, and while some sought mutual support from carers groups, for many the responsibilities and pressures faced were both stressful and isolating. Here, a 92-year-old woman reflects on the experience of looking after her 89-year-old sister suffering from dementia and shares how the responsibility means she neglects her own needs.

At night ... she is anxious and I feel scared. I just have to 'salt and pepper her'...and eventually she calms down. But by then she's in my bed – then she wants to get up and go to the toilet – it's disturbing – I have to get up. ... Sometimes she forgets to put her nappies on and then there's wee all over the bed... at the end of the day I feel like I'm going to fall down....(BC2)

iii. Coping mechanisms

Both patients and relatives demonstrated a number of coping mechanisms to protect them against the uncertainty and potential bleakness of their circumstances. The extent to which patients were able to acknowledge their own condition helped some to maintain equanimity—while others were fiercely avoidant of dwelling on their prognosis. Humour was commonly used to lighten the tone as was a pragmatic approach to wanting to make the best of what was left.

Patients

Different coping mechanisms were apparent in relation to accepting their circumstances; for some, refusal to acknowledge the severity of their condition and not talk about EoL was the preferred option. The emphasis for a number of patients was on living life to the full, often using humour to see their way through the uncertain landscape lying ahead.

I was in hospital for 2 to 3 weeks and it's been downhill since then. First thing in the morning I'm dreadful... nothing is right. My breathing is all wrong... I'm not one though for bed. I put my gown on – and sit and put the TV on – just for the noise. I take my time, make my porridge, sit and have my nebuliser – and just gradually, gradually.... (BP3)

And in a similar vein, Mark, with terminal cancer describes his appetite for life.



I don't see it as 'fighting it' – I see it as 'living my life'. I don't think you can fight this – it will win in the end – so it's not a fight in that sense – but what I want to happen is that the time I have left I should live and enjoy. (BP2)

For a number, acknowledging impending death appeared to bring calm and meant they could disengage from further clinical treatments. Acceptance of the end, however, was not always dealt with in the same way by family or clinicians. One patient, spoke about her wish to die in hospice rather than hospital but admitted that while she had tried to talk about it with her sons, they had found it hard.

I've got no fears talking about it – it's better out. If nobody knows what you want you're not going to get what you want. But my children – no – they don't want to contemplate it. (BP6)

And here a frail woman living at home is clear about the circumstances in which she would not want to be resuscitated.

One of the questions the doctor asked was whether I wanted to be resuscitated if my condition got worse. I said that I didn't want that. So I'm down as DNR {Do Not Resuscitate} if my breathing stops. ... I don't want to be a vegetable or a burden to anyone. (CP4)

Tensions were evident where the position of family, clinicians or the legal position in relation to euthanasia obstructed patient wishes. One patient, for example, described how she had felt duty bound to continue chemotherapy, going against her own inclinations because she believed she would be letting her clinician down. The most desperate examples of patients wanting outcomes not accessible within the current system pertained to euthanasia. Although such cases were at the extreme end of the spectrum, there were a small number of patients who were looking for a way to put an end to what they felt to be a miserable existence. One frail, emaciated, 77-year-old living in a care home, lay on his bed, his breathing raspy and laboured, repeating the refrain:

What I really want now – is to end the lot – somewhere quiet – do you know how I could do it? I want to end the lot. I want peace and quiet. Do you know how to do it? (BP4)

Relatives and unpaid carers

While taking on the burden of responsibility, relatives tended to be pragmatic—acknowledging that a point would come when they could no longer cope and they would need to relinquish care to a hospital or care home. Such decisions were not taken lightly and were often riddled with guilt and a sense that they were somehow letting their relative down.

Well, we want to try and avoid it – but yes of course if she needed it and would benefit from it she would go

to hospital... I know it's mean to say this – but she'll have to go into a home. (AC8)

Recognising and supporting the EoL wishes of sick relatives was difficult and complex; relatives struggled with the implication that accepting imminent death somehow implied a lack of love on their part. However, it appeared, in most cases, when relatives could see the level of pain and frustration experienced—they supported 'do not resuscitate' plans, understanding this would mean suffering would not be extended.

DISCUSSION

This study offers a particularly important and largely hidden perspective on the experiences of frail older people and their carers/relatives at the EoL—many of whom were living either at home or in care homes and suffering a range of chronic co-morbidities. Results show that while there were issues with patients not feeling listened to or occasionally being treated with a lack dignity by medical staff, on the whole most clinical healthcare received favourable reports. Clinicians and medical treatments were generally highly praised. The areas that caused most anger and upset related to: (1) patients feeling objectified by the system and (2) issues around accessing social care and psychological support which were reported to be hard to reach, variable in quality and fragmented. In this sense, service provision at the EoL does not align well with the priorities espoused by patients. Chochinov's¹⁶ work is relevant here, he recognised the importance patients attach to holistic care and used the metaphor of a patient's thread, asserting that to deliver respectful care a doctor must see their patient as a person; to touch the thread that roots their patient as a social being to the real world. A failure to see the patient as a 'whole person', Chochinov warns, risks undermining their sense of self, representing a repudiation of personhood.

The impact of patients living longer with increasing numbers of comorbidities and requiring more care was evidenced in the accounts of both patients and carers and at times negatively affects the mental health and psychological well-being of both parties. As society is invested with the potential to stay alive for longer, we must become more courageous about listening and attending to the priorities of those the system purports to care for.

Despite efforts to integrate health and care services they appear, most of the time, to co-exist, moving along in parallel and iniquitous trajectories where social care is often seen as the poor cousin of the better resourced and higher status health service. The resulting jigsaw of fragmented services was perceived by participants in this study as both hard to access and lacking coherence. Service provision appears to lack clear strategic oversight, failing to consider the priorities of those service users who lack the agency to make their voice heard. Budgets simply follow patterns set in previous years with health budgets growing to embrace new medications

and sophisticated technology while the science and status of social care remains largely unchanged. Whether the merging of health and social care into a single government ministry will improve integration and result in better alignment of services with patient priorities remains to be seen.

What is evident is that the rapidly changing population demographic places increasing demands on our health and social care system. How these pressures impact on the realities of finite budgets and health economics, not to mention arguments about choice, quality of life, respect and dignity, demands further interrogation. The reframing of death and dying by modern medicine and the tenacious drive towards avoiding death at times eclipses the impact this has on other areas of our lives, both in terms of the cost (materials and staff resource) and the human experience (quality of life), that were alluded to by many of the participants in this research. Policy papers may consider ways to accommodate an ageing population, yet, despite finite budgets for health and social care, rarely ask whether the government should actively be pursuing a policy to increase the length of life without considering the implications more broadly and holistically. Indeed, the current UK government vision is to ‘add years to life and life to years’, achieving an extra 5 healthy years by 2035.¹⁷ Alongside this, the complexity and sensitivity of discussions around EoL are highlighted by an amendment put forward in March 2022, to hasten progress of the ‘Assisted Dying Bill’ in the UK Parliament, being blocked by the House of Lords.¹⁸

The findings of this study suggest an imperative to revisit the prevalent biomedical model and to find ways to challenge the current status-quo determining how need is prioritised and how resource allocation flows from this. More research is needed to assess the lived experience of care provided at home in relation to relatives (often acting as unpaid carers), paid carers and patients, and to use this to take a broad view of how funding for health and social care should be re-aligned, to fit better with patient priorities.

One challenge, raised by our findings, is to find a way to align patient priorities particularly relating to the importance of relational care, with available services within the current health and care system. The problem of how patient priorities should be reflected in public policy is challenging, demanding perhaps some sort of system of weighted prioritisation, whereby the perspectives of those at EoL (alongside the perspectives of clinicians and policy makers) are incorporated into a formula for determining the spending of public funds. The pattern observed over the last decade of increasing the spend on clinical health and medical provision, while cutting the allocation to those relational issues so highly valued by patients (including funding to social care), urgently needs to be addressed.⁴

CONSTRAINTS

RE proved an appropriate method to explore and test putative mechanisms and theories with which to frame the enactment of effective EoL policies, a process which is discussed elsewhere.⁶ In relation to the focus of this paper, the appropriateness of the use of the realist interviewing technique is worth considering. The interviewing style is based on a ‘teacher/learner relationship’ where the interviewer introduces the interview by subtly communicating the conjectured theory—giving the respondent the opportunity to either support or refute these ideas. While this was unproblematic with professional respondents, it soon emerged that this style of interviewing was not easy, or perhaps even appropriate, when applied to interviewing patients (and to a lesser extent relatives) at EoL. As the case studies progressed, for both ethical and logistical reasons, we began to question the appropriateness of this type of ‘interviewer’ led technique. The style was often conversational, following Kvale’s¹⁹ vision of the interview as a conversation that co-produces and co-creates knowledge.

At times, a different interview style was adopted, notably that of ‘curious listener’. The question ‘what is important to you now?’ was asked, in response to which ‘conversations’ were started in which a number of themes were identifiable. We suggest that in interviews with vulnerable groups this technique may help address the power imbalance between interviewer and interviewee and be a more appropriate than traditional RE methods. Often, accounts of major life events were presented: the death of a husband, son, wife or daughter; stories of immigration, of fitting in to a foreign country; stories of children going astray or the importance of family. The sense that emerged was of people wanting to review the big events that had occurred in their life, to understand them and tie things together, so that they could more easily accept the end. It is our intention to explore these issues, particularly the methodological challenges relating to interviewing patients at the EoL, in a further paper.

It should also be acknowledged that the case study approached adopted in this research privileged depth of understanding over generalisability. All three sites were London based, all with highly diverse communities and all with wards characterised by high levels of poverty. London has demographics which distinguish it from the rest of England, namely there is significant ethnic diversity, a younger age profile and LE is longer than national average.²⁰ While this bias means findings cannot necessarily be generalised to geographic areas beyond London, we are confident that findings presented here identify common issues experienced nationally and form an important part of a multi-layered truth.

Our positionality as researchers and the impact this has on research outputs should also be noted. This piece of research was in part motivated by an interest in attempting to interrogate the process by which policy decisions around clinical and social care are formulated and the observation that clinical care is often financially



privileged. We acknowledge that the researcher, as the primary instrument of data collection and analysis, has control over both data gathering and analysis which inevitably impacts on outputs.

CONCLUSION

Older people confront the EoL in different ways and their experiences are impacted by a myriad of social, economic and individual factors. Currently, there are few comprehensive tools to evaluate what works, and for whom, and in what circumstances in this arena and there is a paucity of qualitative research reporting on the experiences of older people, particularly those in non-clinical settings.^{10 21} The voice and priorities of those at the EoL are consequently often overlooked, and there is a tendency to prioritise clinical care over social and relational needs. Researching EoL is an area of study fraught with logistical, moral and ethical challenges—yet unless efforts are made to record the experiences of those at the EoL and to feed this into policy and practice, there is a danger that the needs and priorities of this vulnerable group will go unrecorded and largely overlooked. The findings demonstrate that all too often the needs of the patient are packaged into different service areas; clinical needs on the one hand and social needs on the other—often leading to a sense of fragmentation, frustration and obstruction.

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Annex 1

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklistTong et al 2007, 32 item check list: <https://academic.oup.com/inghc/article/19/6/349/1791966>

Domain 1: Research team and reflexivity			
Personal characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	RB (p.6).
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	RB: MSc, PhD PW: PhD, MSc, BEd (Hons), RN, NDN CB: MA, MB, BChir, FRCP
3.	Occupation	What was their occupation at the time of the study?	RB: PhD student PW: Professor of Primary and Community Care CB: Clinical Professor of Palliative Medicine
4.	Gender	Was the researcher male or female?	All female
5.	Experience and training	What experience or training did the researcher have?	RB: Extensive experience of managing health related social research PW: leader of the Kent Academic Primary Care Unit (KAPCU); reader in Patient Experience in the Centre for Research in Primary and Community Care at the University of Hertfordshire; NHS community nursing. CB: Led a project researching Hospice at Home services in England; consultant and clinical lead in Palliative Care at Medway Community Healthcare CIC; experience in research as a local Principal Investigator for national portfolio studies in palliative care.
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	No
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>E.g. Personal goals, reasons for doing the research</i>	Participants were aware of the study aims and objectives
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>E.g.</i>	The interviewers training and occupation were reported.

		<i>Bias, assumptions, reasons and interests in the research topic</i>	
Domain 2: Study design			
Theoretical framework			
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study? E.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	The broader study from which this paper is drawn followed a theory-driven, Realist Evaluation (RE) methodology and comprised a scoping study followed by 3 case studies conducted across London Clinical Commissioning Groups between November 2018 and November 2019 (p.5).
Participant selection			
10.	Sampling	How were participants selected? E.g. purposive, convenience, consecutive, snowball	The sample of patients and relatives/carers was selected purposefully through initial contacts made by professionals who were active in local EOL network meetings (GPs, consultants, nurses, allied care professionals) (p.6).
11.	Method of approach	How were participants approached? E.g. face-to-face, telephone, mail, email	Initial contact made via professional, followed up face to face or telephone (p.6).
12.	Sample size	How many participants were in the study?	43
13.	Non-participation	How many people refused to participate or dropped out? What were the reasons for this?	Professionals mentioned this research to a number of their patients to gauge levels of interest – only a minority had the stamina/will to take part. The number of participants not interested in participating was not recorded. 4 patients who initially agreed to take part died or were too ill to participate at the time of interview.
Setting			
14.	Setting of data collection	Where was the data collected? E.g. home, clinic, workplace	Home, hospice, care-homes, hospital (p.5).
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	On occasion the patients and their carers/relatives were interviewed together (Annex 1).
16.	Description of sample	What are the important characteristics of the sample? E.g. demographic data, date.	Inclusion and exclusion criteria provided in Table 1. Annex 1 provides demographic data.
Data Collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Topic guide provided in supplemental material (Annex 2).

18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio recording (p.6).
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Yes, after the interview.
21.	Duration	What was the duration of the interviews or focus group?	40 minutes to 1.5 hours
22.	Data saturation	Was data saturation discussed?	See discussion on saturation p.5
23	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No. To ensure accuracy of transcriptions, each transcript was verified with the audio recordings prior to data analysis.

Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Initial coding carried out by RB. The key stages of analysis were discussed with the project team and samples of coding were scrutinised across the team to ensure consistency of interpretation (p.7).
25.	Description of the coding tree	Did authors provide a description of the coding tree?	Annex 3 (supplemental materials) provides illustrative quotes to show how codes were used to arrive at broader themes (p.7).
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Coding involved both inductive and deductive analysis (p.7).
27.	Software	What software, if applicable, was used to manage the data?	QSR International Pty Ltd. NVivo qualitative data analysis software, Version 12, 2018.
28.	Participant checking	Did participants provide feedback on the findings?	No but findings were presented to the 'Opening Doors to Research' PPI group in Kent (p.5).
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? <i>E.g. Participant number</i>	Yes
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes, the quotes explicate the themes as presented.
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes, the major themes are presented throughout the results section with representative quotes.

32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes, we have provided the name of the main themes with discussion of diverse cases in the results section.
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Annex 2

Table 1a: Interviews with patients by case study site showing basic demographics, clinical condition, interview location and method of recruitment (n=21)

	Setting	Age of patient	Recruitment method	Ethnicity	Gender
Site A (n=5)	Care home: 3 Hospice: 1 Home: 2	70 + years: 1 80 + years: 2 90 + years: 2	Care home manager: 3 GP: 1 Hospice clinician: 1	White British: 5	Female:4 Male: 1
Site B (n=7)	Care home:2 Hospice: 2 Home: 3	70 years +: 4 80 years +: 2 90 years +: 1	Care home manager: 3 GP: 3 Hospice clinician: 2	White British: 6 Black Caribbean: 1	Female:5 Male:4
Site c (n=9)	Hospital: 1 Home: 9	70 years +: 7 80 years +: 2	Home: 8 Hospital: 1	White British: 5 White European: 4	Female:7 Male:2

Table 1b: Interviews with relatives/carers by case study site showing basic demographics, recruitment method and place of interview (n=22)

	Setting	Age of carer	Recruitment method	Ethnicity	Gender	Relationship to person cared for
Site A (n=10)	Telephone: 9 Care home:1	40+ years:1 50+ years:4 60+ years:1 70+ years:2 80+ years:1 90+ years:1	Carers forum: 4 GP: 5 Palliative care consultant:1	White British: 5 White European: 4 Black Caribbean: 1	Female:6 Male:4	Parent: 9 Spouse: 1
Site B (n=4)	Home:2 Telephone:2	40+ years:1 70+ years:1 80+ years:1 90+ years:1	Carers forum: 3 Hospice: 1	Black Caribbean:1 Indian:1 Mauritian:1 White British:1	Female:4	Sibling:1 Parent:1 Spouse: 1 Volunteer through hospice:1
Site C (n=7)	Home: 6 Telephone:1	50+ years:1 70+ years:1 80+ years:4 90+ years:1	GP: 3 Patient: 3 Palliative Care Consultant:1	White British: 5 White European: 2	Female 2 Male 5	Spouse: 5 Parent: 2

Annex 3.

Topic Guide for patients and relatives/carers participating in Case Studies

Research study investigating the care experiences of older people needing more support and care. Does national policy help guide local practice?

Date: 13/07/2018

- Introduction – background to study
- What is your experience of the care you have received (or the treatment of the person you are caring for) over the last few months? This may be care from doctors, nurses, volunteers, therapists, social workers etc.
- It may be helpful to think about a specific episode and ask:
 - Who came to see you?
 - What did they do?
 - Was that how you wanted it?
 - Is that what normally happens?
 - Who else comes to see you
 - What are the things they look forward to most?
 - What are the things they find most helpful? What else would be helpful?

Prompts:

- What aspects of the care that you have received/are receiving, have been/are the most helpful to you or the person you are caring for)? Do you have a care plan in place? Advanced Care Plan? Advanced Care Directive?
- Have there been things that have got in the way of you/your relative receiving better care? Can you tell me about them?
- Do you feel that there was any care/ support that was not provided, or that you feel could have been done better?
- Have all your needs been addressed in equal measure or have some been easier to meet than others? (Probe: keeping you comfortable/reducing pain/providing clinical (medical) treatments/providing social support/providing assistance for helping you to eat/supporting family and carers/spiritual support/other)?
- What does good care mean to you?
- To what extent do you feel you/your relative/friend are:
 - treated as an individual?
 - involved in decisions?
 - have fair access?
 - care is coordinated?

- comfort is achieved?

- 1. When thinking about your care/ the care of your relative/friend do you make any distinction between health care (doctors/nurses) and social care (people who help with washing, cooking, counselling, cleaning etc)

Aspirational

If it was up to you to determine what type of care is offered to people in your situation what would your priorities be?

Annex 4

Table 2a

Theme: Patient reflections on the clinical and social care received – illustrative quotes

Theme: Patient reflections on the clinical and social care received	
Codes/Subthemes	
i.	<p>Being treated with empathy/dignity:</p> <ul style="list-style-type: none"> • <i>You can have your own routine. They'll hold meals over for you – they'll save it up and you can have it when you're ready. Anything within reason you can have (CP3 – palliative care ward)</i> • <i>The only place I've felt like I was treated with dignity was the St Joseph's hospice. They treated you with dignity. (BP4)</i> • <i>It's hard to explain what that means – its when you feel like a person again and not a number – its just a feeling. (AP4)</i>
ii.	<p>Responsive pain relief</p> <ul style="list-style-type: none"> • <i>Sometimes I wake up feeling the most awful pain – feeling as well I've been pinned to the bed. So she's started me on pain killers which I take every morning and evening – there's also a mixture of other pain killers which I can have during the day if I need a top up. I just buzz and ask for my pain relief and they'll bring it to me. (CP3 – palliative care ward)</i>
iii.	<p>Relational care</p> <ul style="list-style-type: none"> • <i>They were very good to me in hospital. They looked after me and were there when I needed them. They were very kind – there's a lot of good nurses there. (BP7)</i> • <i>But my doctor.... when he comes he sits and talks to me about cricket, you know, he's nice. (CP8)</i> • <i>He's one in a million. Dr Singh. He'll sit and listen and give you the right answers and he won't fob you off. (CP7)</i> • <i>I'd {like to} go back to the old days when you could go and see your local doctor cos he was local for that area. You'd go and see him and he'd say 'hello Robert – how are you doing? Did you sort out your sore leg? And what about your mother – how's she doing?' We all knew each other. Now it's abrupt: 'yes? What's wrong?' (CP9)</i> • <i>We have a nurse who gives out medication and sees us at least three times a day. I can ask to see the GP or the nurses can refer me. They're very good – you can talk to them. (AP1)</i> • <i>I had a horrid time in hospital. I had an infection – which I got during my time in hospital – so I was put in a room on my own and just left to fester. I don't really remember much of it. I had to be shut in and no one was allowed in without masks and protective gear. I thought well – its you that's given me the infection – don't treat me like a leper! It doesn't seem to make much difference. There was no proper communication. You'd be lying in the bed and three or four (staff) would come in and look at you. They'd all be discussing this that and the other – then they'd go off out the room – it was like they didn't notice ME. There was no 'Hello Mrs x, I'm 'Fred Dinkum' – I'm the local this or that'. I was just an object lying in a bed who they came and looked at and that was it! (AP2)</i> • <i>I have a doctor who I like. Dr Powell. He comes to see me at home – he's retired actually – he only works 2 days/week but he still seems me. I've known him 40 odd years (BP8)</i> • <i>Whilst my carer was away I said I don't want some stranger who I don't know coming in to give me a shower. I said it's embarrassing enough needing help to have a shower – without having to have someone I don't know -but they don't seem to take any notice. (CP8)</i>
iv.	<p>Instances of poor care</p>

<ul style="list-style-type: none"> • <i>But they used to bring his tea out for him and they took it away before he'd even attempted to eat it. They never try to encourage him. I had a word and said – I know you're busy and have other things to do – but if you could just cut up his food for him he would manage better. (CP4 – observations from hospital bed)</i> • <i>Although I kept telling them I needed lactose free milk I didn't always get it. I get awful pain and wind with cows milk. (CP3)</i>
<p>v. Feeling listened to</p> <ul style="list-style-type: none"> • <i>I feel listened to. I can ask for anything within reason. Nothing has been refused. Yesterday when the doctor was here I said 'you know what – I'd love a Bacardi and Coke' ..Well she said – 'there's no reason why you shouldn't have one here. Some of your water tablets may activate your kidneys a bit more – but that's why it's called a kidney flush. They treat me as a human. So, I've given instructions for someone to bring me a Bacardi supply and Jim will bring me in a coke every evening if I want one! (CP3)</i> • <i>The important thing is that they respect my solitude. They don't stroll in here and assume that I want to chat. They do not do that – they come in to do what they have to do. If I seem to want to chat then they'll talk to me – but if I'm not in the mood they won't. For me that's the important thing. (AP3)</i> <i>The most important thing is for them to listen to me. (CP5)</i>
<p>vi. Fragmentation of the health and social care system</p> <ul style="list-style-type: none"> • <i>The problem is I often don't really know who to call. (AP2)</i>
<p>vii. Problems with access</p> <ul style="list-style-type: none"> • <i>Everything is online. That's not great as you get older. There's no one to speak to face to face. Quite a lot of people are isolated.</i>

Table 2b. Theme: Carer reflections on clinical and social care received – illustrative quotes

Theme: Carer reflections on the clinical and social care received	
Codes/Subthemes	
i. Satisfaction with much of clinical care received	<ul style="list-style-type: none"> • <i>Towards the end she was having trouble breathing – the ambulance service came out a couple of times – and again they were absolutely fantastic. (AC7)</i>
ii. Challenges with social care	<ul style="list-style-type: none"> • <i>She's never sure who she's going to see on the day. (CC5)</i> • <i>And she {the doctor} said you'll have carers coming in. I didn't want it at first. I thought I can do it all myself. But now I just do the basics (cooking, cleaning and my own stuff) and I leave the carers to it. Its enough. (CC7)</i> • <i>She was a nice girl but she had to speak into her phone and do Google Translate. You can't do that with someone who is frail and elderly. (AC3)</i> • <i>Language is a big issue for her. She's Italian and doesn't understand much English. (AC8)</i>
iii. Feeling validated/listened to	<ul style="list-style-type: none"> • <i>In the end it was only the pharmacist who came to do her blister pack as she was being discharged, who actually listened to me and got her taken off the anti-depressants. (AC1)</i>
iv. Language/communication issues	<ul style="list-style-type: none"> • <i>Some carers don't speak much English. Yesterday I when I was worried about the carbon monoxide – I was asking one of the carers how mum's breathing was – but she didn't understand the question (AC10)</i> • <i>The trouble for us is that the English we learn isn't equal to the English that indigenous</i>

<p><i>speakers talk here. We just speak simple English – so we can't argue with you – if you ask them a question they won't reply they'll just ask you a question. (BC2)</i></p>
<p>v. Fragmentation of the health and social care system</p> <ul style="list-style-type: none"> • <i>So I would phone the community rehab team and they told me they'd never received a referral and to call the GP. So I called the GP and they told me to call the ward who had discharged her. The ward then said to call the GP – and so you start going round in circles with everyone passing on the buck. It's the same with the DN – I called the GP to ask if we could have one and again the GP said the ward should have sorted this out. You end up beginning not to care about anything. (AC2)</i> • <i>For someone in mum's situation {the housebound frail elderly} – if you had a point of contact... they would have an idea of her as a whole person and could coordinate the different services around her. (AC2)</i>
<p>vi. Learning to be more assertive</p> <ul style="list-style-type: none"> • <i>I said 'oh no I don't think so. This is the fourth time I've been here. You're going to keep him. I said 'stick him in the car park for all I care. I'm not taking him home. ... The doctor, he was a lovely man, and he said to me, 'if you hadn't insisted I wouldn't be talking to you here. I'd be talking to you at the side of a grave. (AC1)</i>
<p>vii. Resource constraints</p> <ul style="list-style-type: none"> • <i>The bottom line is that all this austerity has cut across everything and a lot of families just don't have a connection or the resources to enable much support. (AC7)</i>
<p>viii. Iniquitous access to services</p> <ul style="list-style-type: none"> • <i>If I hadn't taken her there she wouldn't have gone – there was no service to pick her up. But it was very good – it did her a lot of good. She became much more mobile. (AC8)</i>

Table 3a.**Theme: Challenges to good patient mental health and wellbeing - illustrative**

Theme: Patient mental health and wellbeing	
Subthemes	
i. Isolation	<ul style="list-style-type: none"> Well, you can see how many people there are around here – no one...no companions. (BP4)
ii. Sense of purpose	<ul style="list-style-type: none"> I don't do any of the group socials within the home because my oxygen lead only reaches to the top of the stairs. (CP3) I cannot bring myself to thank either the medical profession or the pharmaceutical industry for keeping me alive as long as they have. I think I'm absurdly old and I wish I'd died at some sensible time like, I don't know, late seventies, mid eighties, something like that. (AP3)
iii. Anxiety	<ul style="list-style-type: none"> I'm very frightened of falling. (AP2) What bothers me more than anything else is a failing memory. (AP3)
iv. Confidence	<ul style="list-style-type: none"> You lose your confidence after things like that. (BP8)
v. Low mood	<ul style="list-style-type: none"> I miss everything. I get my lows and my highs. (BP5) This last couple of years have been hard. Some days I feel so low. I'm sorry to say this but I don't want to be around anymore. (CP4) I've got depression....I used to go to a place in xxxx to talk about my depression. It all started when I had cellulitis in my leg – and that's what left me with lymphedema. (CP8) She gets very depressed – she does withdraw into herself but especially at night she will talk to me about how she's struggling. (AC3) I'm sorry I'm a miserable sod. They say money doesn't help life – but it does. If I had money I'd be in a five star hotel (BP4)

Quotes**Table 3b****Theme: Challenges to carer mental health and wellbeing - illustrative Quotes**

Theme: Carer mental health and wellbeing	
Codes/subthemes	
i. Isolation	<ul style="list-style-type: none"> I thank you for talking to me – nobody comes to our house – its only the carers who visit. (BC2) The joy of the carers hub is that it brings people together – many of them are more isolated than me .. some people have no one. There are days of course when it all just seems too much. (MC2)
ii. Burden of care	<ul style="list-style-type: none"> I can't look after myself – how can I do that? I have to cut her hair, her toenails– everything. I can't just leave her and say 'never mind – her nails are growing – if I let things go I would find it harder in the end. I can't sleep – at the end of the day I feel like I'm going to fall down on the bed. (BC2)

- *I'm actually having some counselling sessions at the moment – the psychologist there has established that I'm suffering depression and I need to do something about it. I don't feel stressed when I'm looking after my mum – but sometimes when things go wrong with her, or her care, for example the moisture lesions at the moment – that can make me depressed and anxious. (AC3)*
- *I was so tired and I just said – 'I just want you to know that you took the tablets at 9 o'clock. You need to believe me – just go to bed - go to bed.' I was a bit cross actually. It was anxiety. (AC8)*
- *I found all the tablets she was supposed to have given under her feet on the floor. I think I must have just walked in at the wrong time and she'd hidden them. Well then you begin to think you need to reschedule your day - so you are there for all the important moments. (AC2)*
- *You have to keep on the ball because you worry that otherwise it just won't happen. (CC5)*

Table 4a

Theme: Patient coping mechanisms – illustrative quotes

Theme: Patient coping mechanisms	
Codes/Subthemes	
i. Making the best of it	<ul style="list-style-type: none"> • <i>I don't spend long everyday making myself up – just two minutes. I put a bit of powder on. If I don't do that people think I'm ill. I've not got any colour. People say 'are you alright?' – and I say 'I've just not got any make up on... I've got used to things being rough my darling – after 2 and a half years – it's not going to change overnight. When I go to bed - I'd love it if I could wake up and not wobble all over the place the next day – but it goes on – you can't feel sorry for yourself.... (CP4)</i> • <i>Oh, the people here ... they ask me often if I would like to go down into the garden. But I don't want to. I'm a lucky man in that I've discovered solitude – and it's a great discovery. (AP3)</i> • <i>The worst bit of that is getting the old catheter out. I tell them just to give it a quick pull... I get on very well with the nurses here. They come in and see me three times a day – they're excellent and we have good fun together. (AP1)</i> • <i>I go into the doctor on my scooter with my oxygen attached in a little cannister. I've got it down to a fine art. People say I look fit. I've always been very active but now I can only do so much and then I'm knackered mentally and physically. Washing up makes my back ache, and my lungs ache. I can feel the pressure on my lungs if I'm standing too long. (BP3)</i> • <i>I don't do any social things with other residents. I don't think I mind this because I don't think I'd hear them and they wouldn't hear me. I get on very well with the nurses. Most of the carers are fairly good. (CP2)</i>
ii. Setting limits	<ul style="list-style-type: none"> • <i>If I go outside it disturbs my solitude. I start getting confused about what's happening. I see faces I haven't seen for ages and all that sort of thing – so I've got to guard my solitude and look after it. (AP3)</i>
iii. Independence	<ul style="list-style-type: none"> • <i>I do my own shopping.... Come and see my fridge. I look after myself. It's well stocked. I have a cleaner– she does things like clean around things I find heavy going – and changes the sheets. Those elastic ones that you have to pull up – I can't do them no more. So she does that and helps me with anything I want. She's the only one who comes in. (CP9)</i>

<p>iv. Accepting the end of life</p> <ul style="list-style-type: none"> • <i>No if I'm going I want to go. In fact I have expressed it in this way. (AP3)</i> • <i>My son's going to bury me at Windsor he reckons (he laughs). I love Windsor. So my son says 'I'll bloody bury you there! (CP7)</i> • <i>I don't like talking about 'end of life'. I don't mind the word hospice though – it's just a place you go when you're sick. (BP8)</i> • <i>But I keep myself busy and get on with things. People ask me how I remain resilient. It's like Samuel Johnson said: 'nothing focuses the mind as much as when a man knows he's going to be hung in two weeks'. We're all in the same boat. We all know we're going to die at some point. The challenge then becomes not worrying about the impending event of death – but using the time that is left to the best of your ability. It's not strength – you just don't have any other option. For me it's not about winning the battle – it's about living my life as fully as possible. (BP2)</i> • <i>I don't particularly want to go home – because later on they'd walk around and say, 'oh mum died there'. I don't want them to have those memories. Oouff. NO. I don't want that happening to the kids – having all those memories of 'that's where mum was'. I don't want that. My husband probably wants me at home, but we just haven't really spoken about it. Ideally, I'd rather just not wake up in the morning. That's what I think. Never mind. (BP6)</i> • <i>One of the questions the doctor asked was whether I wanted to be resuscitated if my condition got worse. I said that I didn't want that. So I'm down as DNR if my breathing stops... I don't want to be a vegetable or a burden to anyone. Both sons have accepted that. (CP3)</i> • <i>If I got cancer again I wouldn't want radio therapy or chemotherapy if there was pain attached to it or nasty side effects. I can't cope with that. I can't cope with a lot of pain. (CP5)</i>
<p>v. Varying levels of engagement with prognosis</p> <ul style="list-style-type: none"> • <i>Yes – we're just waiting for the results of my scans – you know the one's I had on the last two Sundays – but we go out and walk about. The doctor will notify us of the results. I don't really know what they are looking for – or if I did I've forgotten. But I did go yesterday to the hospital for a blood test. (CP2)</i>
<p>vi. Humour</p> <ul style="list-style-type: none"> • <i>Ask me anything you like. I've not got a boyfriend. I don't have a sex life – and I don't do it myself either. What do they say ... masturbation {laughs uproariously} (CP5)</i>

Table 4b**Theme: Carer coping mechanisms – illustrative quotes**

Theme: Carer coping mechanisms
Codes/Subthemes
<p>i. Acceptance</p> <ul style="list-style-type: none"> • <i>I understand that my mum, who is in pain all the time, doesn't want to go on suffering. (CC4)</i> • <i>I said 'no I don't want him to be revived'. He wanted to die. (AC6)</i>
<p>ii. Pragmatic</p> <ul style="list-style-type: none"> • <i>Well, we want to try and avoid it – but yes of course if she needed it and would benefit from it she would go to hospital. With her dementia – when it gets worse and we can't cope with her any longer. I know it's mean to say this – but she'll have to go into a home. But at that stage I don't think she'll even know who we are. (AC8)</i>

- *The doctor did ask us if things got really bad if we would want her put on life support? I said 'well you had better do what you think is the right thing. I don't want her suffering and she's not in the position to say what she wants. What can I do?' (BC2)*

iii. Low expectations

- *But to be honest with you, where I'm at at the moment, rather than feeling more supported through officialdom, the way I'm coping is by feeling more and more resigned to doing it on your own. (AC2)*

iv. Humour

- *Well, she's coughing up blood and we're not sure if she's going to last the night. And they ask if she's got any false parts – dentures etc. And we say no, no. And she pipes up – yes, I've got a full set of dentures. I've lost all my teeth. And Alex and I both thought – 'well when the fuck did that happen? That's news to me! And she says, 'I've had all my fucking teeth out'. And I say well that's news to me! CC5*