Title: Living with diabetes alongside a severe mental illness: A qualitative exploration with people with severe mental illness, family members and healthcare staff

Running title: Managing diabetes with a severe mental illness

Sue Bellass[1a], Jennie Lister[1], Charlotte Emma Wray Kitchen[1*], Lyndsey Kramer[2], Sarah Louise Alderson[3], Tim Doran[1], Simon Gilbody[1], Lu Han[1], Catherine Hewitt[1], Richard Ian Gregory Holt[4], Rowena Jacobs[5], Stephanie Louise Prady[1], David Shiers[6], Najma Siddiqi[1,7] and Johanna Taylor[1]

[1] Department of Health Sciences, Seebohm Rowntree Building, University of York, Heslington, York, YO10 5DD, UK.

[2] Department of Sociology, Wentworth College, University of York, Heslington, York, YO10 5NG.

[3] Leeds Institute of Health Sciences, University of Leeds, Worsley Building, Leeds, LS2 9LN, UK.

[4] University of Southampton, Faculty of Medicine, / Southampton National Institute for Health Research Biomedical Research Centre, University Hospital Southampton NHS Foundation Trust, Southampton General Hospital, Southampton, SO16 6YD, UK.

[5] Centre for Health Economics, University of York, Alcuin A Block, Heslington, York, YO10 5DD, UK.

[6] Division of Psychology and Mental Health/Greater Manchester Mental Health NHS Trust/Primary Care and Health Sciences (Keele University), University of Manchester, Manchester, M13 9PL, UK.

[7] Bradford District Care NHS Foundation Trust, New Mill, Victoria Road, Saltaire, Shipley, Bradford. BD18 3LD, UK/ Hull York Medical School, University of York, Heslington, York. YO10 5DD.

*Corresponding author: Dr Charlotte Kitchen, charlotte.kitchen@york.ac.uk

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[a] Work carried out whilst at the University of York, now based at the Leeds Institute of Health Sciences[3].

Conflicts of interest disclosures:

SLA has received funding from the Wellcome Institutional Strategic Support Fund and a National Institute of Health Research (NIHR) Clinical Trials Fellowship. SLA is a member of the Health Services & Delivery Research funding committee. SG is deputy chair of the NIHR Health Technology Assessment (HTA) Commissioning Board, and a member of the HTA Commissioning Committee, the HTA Funding Committee Policy Group, and the HTA Post-Funding Committee teleconference. CH is a member of the NIHR HTA Commissioning Board (2015-current). RIGH has received honoraria for speaker engagement, conference attendance or advisory boards from: AstraZeneca, Boehringer-Ingelheim, European Association for the Study of Diabetes, Eli Lilly, Janssen, Menarini, Mylan, Novo Nordisk and Omniamed, Otsuka. RIGH was a member of the HTA Prioritisation Committee C (Mental Health, Women and Children's Health) until July 2019. DS is an expert advisor to the National Institute for Health and Care Excellence (NICE) centre for guidelines and a member of the current NICE guideline development group for Rehabilitation in adults with complex psychosis and related severe mental health conditions; a Board member of the National Collaborating Centre for Mental Health (NCCMH); a Clinical Advisor (paid consultancy basis) to the National Clinical Audit of Psychosis (NCAP); these are the personal views of DS and not those of NICE, NCCMH or NCAP. DS has received personal fees from Wiley Blackwell publication "Promoting Recovery in Early Psychosis" 2010, ISBN 978-1-4051-4894-8, joint editor in receipt of royalties, outside the submitted work; personal fees received as member of the current NICE guideline development group for Rehabilitation in adults with complex psychosis and related severe mental health conditions. SB, JL, CEWK, LK, TD, LH, RJ, SLP, NS and JT declare no conflicts of interest.

Novelty Statement

What is already known?

- Diabetes is more common in people with severe mental illness and leads to worse health outcomes.
- Diabetes is commonly 'overshadowed' by mental illness.
- Depression adversely affects diabetes self-management but we know little about severe mental illness.

What this study has found?

- People living with the comorbidity, and staff supporting them, cannot always distinguish between symptoms of severe mental illness and diabetes.
- Managing diabetes becomes difficult when severe mental illness or physical health deteriorates.
- Low mood has a pervasive impact on diabetes self-management in this population.

What are the clinical implications of the study?

- Interventions that help to better distinguish between symptoms of severe mental illness and diabetes are needed.
- More intensive support for diabetes management is needed when mental or physical health deteriorates.
- The role of depression in this co-morbidity should be considered.

Funding

Abstract:

Aims

Diabetes is 2-3 times more prevalent in people with severe mental illness, yet little is known about the challenges of managing both conditions from the perspectives of people living with the comorbidity, their family members or healthcare staff. Our aim was to understand these challenges and to explore the circumstances that influence access to and receipt of diabetes care for people with severe mental illness.

Methods

Framework analysis of qualitative semi-structured interviews with people with severe mental illness and diabetes, family members, and staff from UK primary care, mental health and diabetes services, selected using a maximum variation sampling strategy between April and December 2018.

Results

Thirty-nine adults with severe mental illness and diabetes (three with type 1 diabetes, 36 with type 2 diabetes), nine family members, and 30 healthcare staff participated. Five themes were identified: 1) severe mental illness governs everyday life including diabetes management; 2) mood influences capacity and motivation for diabetes self-management; 3) cumulative burden of managing multiple physical conditions; 4) interacting conditions and overlapping symptoms; 5) support for everyday challenges. People living with the comorbidity and their family members emphasised the importance of receiving support for the everyday challenges that impact diabetes management, and identified barriers to accessing this from healthcare providers.

Conclusions

More intensive support for diabetes management is needed when people's severe mental illness (including symptoms of depression) or physical health deteriorates. Interventions that help people, including healthcare staff, distinguish between symptoms of diabetes and severe mental illness are also needed.

Key words: Diabetes mellitus; bipolar and related disorders; schizophrenia spectrum and other psychotic disorders; comorbidity; self-management; delivery of healthcare

Introduction

Severe mental illness affects around 1% of the population and refers to a group of conditions, which include schizophrenia and bipolar disorder [1]. People with severe mental illness often experience paranoia, feelings of persecution, mood swings, impaired cognition, and lack of motivation which adversely affect activities of daily living [2]. Severe mental illness often occurs in the context of social and economic disadvantage; people with severe mental illness experience stigma, poor housing and lower levels of employment and education [3, 4], which can make navigating complex welfare, social and health care systems more difficult. Further complicating the experience of severe mental illness is the risk of developing type 2 diabetes, which is 2-3 times higher than in the general population [5-7]. A UK study reported around 16% of people with severe mental illness have diabetes compared with 7.6% without severe mental illness [8]. The increased prevalence of diabetes and its complications, in particular cardiovascular disease, are significant contributors to the 15-20 year lower life expectancy for this group compared with the general population [9-12]. Though not fully understood, several factors increase the risk of diabetes and poor diabetes outcomes in this population [13-15] including obesogenic effects of antipsychotic medications [16-18], and health risk behaviours such as poor diet [19], smoking [20, 21] and physical inactivity [22].

People experiencing both conditions face a unique set of challenges, including polypharmacy and navigating different service providers. Likewise, family members and friends may find the added burden of supporting a person with both mental and physical disorders particularly stressful [23]. Difficulties related to the severe mental illness also create barriers to adopting behavioural changes that form a major part of successful diabetes management [24, 25]. Little research, however, has explored the experiences of this comorbidity from the viewpoint of those living with severe mental illness and diabetes [24], and no studies have included the perspectives of those who provide both formal and informal care.

Study aim

This qualitative study aimed to: i) explore the experiences of living with severe mental illness and diabetes and managing both conditions; and ii) understand the circumstances influencing access to and receipt of diabetes care.

The research was part of the EMERALD project which is a mixed methods study designed to increase our understanding about the increased risk of poor diabetes outcomes for people with severe mental illness [26]. The COREQ checklist was completed to aid transparent reporting of methods [27].

Participants and methods

Sampling strategy

People with severe mental illness and diabetes

Eligibility criteria:

- Aged 18 years or over, with capacity to provide informed consent
- Recorded diagnosis of severe mental illness (schizophrenia, schizoaffective disorder, bipolar disorder, depression with psychosis), excluding those experiencing an acute relapse
- Diagnosis of type 1 diabetes or type 2 diabetes
- Living in the community (including supported housing, but not those admitted to acute hospital settings).

To capture a broad range of experiences, a maximum variation sampling strategy [28] was adopted (Table 1). Efforts were made to construct an ethnically diverse study sample, which was important because of the increased risk of diabetes in Black and South Asian populations [8].

Insert TABLE 1 here

Participants were recruited from six general practices (from 10 that volunteered to assist with recruitment) with a range of deprivation scores, from 1 for most deprived through to 10 for least deprived, (a score combining seven domains of deprivation at small area level recorded on the National General Practice Profile [29]), six mental health trusts in the North and North West of England, and via a research database containing details of participants with severe mental illness and diabetes who had previously consented to contact for future relevant research studies [30]. Staff from the recruiting sites initially invited any eligible person they identified and we continually monitored sample characteristics to aim for maximum variation, asking sites to target people with under-represented characteristics towards the end of recruitment. For example, the ethnic profile of our sample of people with severe mental illness and diabetes lacked diversity so we asked sites to focus specifically on recruiting people from a Black or South Asian ethnic group.

We aimed to recruit a minimum of 30 people with severe mental illness and diabetes, after which we monitored data saturation, adding new participants until no new information relevant to the study aim was forthcoming [S31].

Family members and friends

We asked participants with severe mental illness and diabetes to identify family and friends who provided informal support who might be willing to take part in an interview, and identified

additional family member participants through the existing research database. As people with severe mental illness and diabetes are less likely than the general population to have adequate social support [S32], a lower target sample size of 15-20 people was set.

Healthcare staff

Healthcare staff involved in the commissioning or provision of mental or diabetes healthcare for people with severe mental illness (in primary and secondary care), were identified through university networks or the sites that were recruiting people with severe mental illness and diabetes. To gain a broad range of perspectives, we initially planned a purposive sample of 15-20 people from several staff groups: commissioners/managers, clinicians and other staff, with an aim to continue recruiting participants until we achieved data saturation.

Contact and consent

All potential participants were provided with written information about the study and asked to return a response form or contact the research team if they wished to participate. Those expressing an interest were contacted by SB (a female postdoctoral social scientist with qualitative research training and experience), who explained the study and arranged and conducted the interview. Written or audio-recorded verbal consent was given by all participants prior to data collection.

Data collection

In-depth semi-structured interviews were employed using topic guides (Appendix 1) developed with reference to existing literature and with input from, and pilot testing with, members of a Patient and Public Involvement panel, DIAMONDS VOICE. Topic guides were designed to cover key areas of interest while minimising participant burden (important for people with severe mental illness-related cognitive and attentional difficulties [S33]), and employed flexibly allowing more or less time for participants as required. Interviews were conducted between April and December 2018, in participants' homes for people with severe mental illness and family members, and at places of work or by telephone for staff. Interviews were audio-recorded and transcribed for analysis.

Data analysis

The Framework method [S34], a form of thematic analysis, was used to analyse the data. This method combines the exploration of *a priori* concepts with the generation of themes derived inductively from the data. This approach enabled us to explore similarities and differences between the different participant groups. A coding framework was developed and applied to the data (undertaken by JL and LK with input from SB and JT), and themes and the relationships between them were identified and developed (undertaken by JL, JT, SB and CEWK). To explore differences

between participant groups, the analysis for each group was conducted separately yet with a dialogue between them to enable cross-group comparison; for example, the coding framework (Appendix 2) for participants with severe mental illness and diabetes was tested against family member and staff data and adapted to be responsive to differing perspectives. To enhance the rigour of the analysis, emerging themes were challenged by data from divergent accounts. This process enabled the development of a more nuanced understanding of the data. NVivo software [S35] was used to manage and code the data.

Themes were developed through team discussions and regularly checked against the codes to ensure that, while abstracted to a more conceptual level, they captured and represented the accounts of participants. The analytic process involved regular discussion with the broader study team including a representative from DIAMONDS VOICE. To assure authenticity of study findings, themes were discussed at two workshops involving people with severe mental illness and diabetes and family members, with one also attended by staff.

Ethics approval

This study was approved by the Greater Manchester West Research Ethics Committee (ref: 18/NW/0005).

Results

Seventy-eight people were interviewed; 39 people with severe mental illness and diabetes, nine family members and 30 healthcare staff. The majority of people with severe mental illness and diabetes (n=30) were recruited from NHS mental health trusts; 7 were recruited from general practices and 2 were recruited from the research database.

Duration of interviews with people with severe mental illness and diabetes was between 17-98 minutes (median=45), between 23-97 minutes (median=52) with family members and between 26-75 minutes (median=43) with staff. Six participants (4 staff and 2 people with severe mental illness and diabetes) declined audio-recording, so detailed notes were made during and immediately after interviews. All interviews were conducted in English apart from one, where a translator was used for an interview with a Punjabi-speaking participant.

The sample of people with severe mental illness and diabetes (Table 2), included 22 men (56%) and 17 women (44%). Schizophrenia was the most common severe mental illness diagnosis (n=22, 56%) followed by bipolar disorder (n=13, 33%). Although the majority (n=36, 92%) had type 2 diabetes, the ordering and duration of diabetes and mental illness diagnoses varied across the sample, as did

participants' experiences of care and treatment. The age of participants ranged from 28-71 years (mean age 53 years), and the sample included seven people from a minority ethnic group. Two participants (5%) were employed, five were retired (13%) and 32 (82%) were unemployed, although several of the retired and unemployed participants had previously been employed.

*** insert TABLE 2 here***

Although friends were included in the definition of a person providing support for someone with severe mental illness and diabetes, all nine participants (see Table 3) were family members (spouses, n=6; parents, n=2; adult children, n=1). Six were women and three men; all male participants were spouses.

*** insert TABLE 3 here***

Healthcare staff participants were from varying disciplines and roles spanning mental health, primary care and diabetes services. Nursing was the most represented profession (n= 13; see Table 4).

insert TABLE 4 here

Five overarching themes were identified from the analysis that featured across participants' accounts of living with severe mental illness and diabetes, and were reflected in the perspectives of many of the staff and family members who took part in the study. These are described below, with illustrative quotes for each theme/sub-theme presented below and in Table 5 (those with type 1 diabetes have been identified with the designation T1). We have also indicated where relevant how participants varied in their experiences, for example drawing attention to instances that were only talked about by a few participants or most. This is to guide the reader through our data and is not meant to infer that similar relationships may exist in the wider population of people living with these conditions, which is not the aim of qualitative research.

insert TABLE 5 here

Theme 1: Severe mental illness governs everyday life

Most participants from all three groups provided detailed accounts of the pervasive effect of mental health problems on daily lives; affecting people with severe mental illness's ability to leave the house, work, retain a driving licence, engage in personal care or household management, make or maintain friendships, and manage appointments. Severe mental illness was also occasionally reported to affect personal finances, although only family members and staff explicitly highlighted

ways in which this affected diabetes management, for example by limiting access to transport and healthy foods.

All three participant groups commonly reported that severe mental illness overshadowed the importance of diabetes, the treatment of which was often *"governed by mental health"* [ES-T2-02, person with bipolar disorder]. Indeed, one spouse noted that "*I know you're looking at diabetes and mental health… but from my point of view, the issues are, without a doubt, the mental health issues*" [ES-T2-17, family member].

The precedence of severe mental illness over diabetes was often most apparent when participants described periods of poor mental health, where the focus was on immediate needs and survival: *"If part of your mind is thinking of suicide, it's like very difficult then, to be particularly panicky when someone says your blood sugar's gone up by two points."* [ES-G2-01, person with bipolar disorder]. For a few participants with severe mental illness and diabetes, there was a sense that diabetes could be addressed in the future, in part because of the less immediate impact on their lives compared to severe mental illness. One staff participant understood this as a lack of optimism from people with severe mental illness that they would live long enough to be affected by diabetes complications, and this sentiment was reflected in the accounts of several participants with severe mental illness and diabetes as they spoke about their health.

A further example of the foregrounding of mental health was found in the majority of participants' accounts of their diabetes care, which they discussed with less specificity and engagement than when describing their mental health care. Descriptions by those with type 2 diabetes were often perfunctory, and even when further questions were asked, participants tended to give little more than brief descriptions of regular checks they received such as blood tests or blood pressure checks. The three participants with type 1 diabetes spoke in more detail about their diabetes care, although they too provided numerous examples of how their mental illness could derail and overshadow their diabetes management.

The focus on mental health and its pervasive presence in people's lives also engendered feelings of powerlessness for several participants:

> *"It's something actually inside of your head all the time … it just keeps going round and re-playing and re-playing … and when am I going to get off the circle? And you can't … I mean it's not like a diet. I mean you can change your diet. You can't change your mental illness."*
> [ES-G3-01, person with schizophrenia]

Taking medication could itself exacerbate these feelings, and a few participants perceived a lack of control over their severe mental illness and its treatment: *"the side effects of the drugs are not good … you wouldn't take them if you had the choice. I mean, I am desperate, so I take my medication."* [ES-T2-16, person with schizophrenia]. Linked to feelings of powerlessness was an acceptance among many participants from all three groups that when mental health problems dominated daily life, diabetes would be neglected, as this participant with bipolar disorder explained, *"When you're mad as a hatter, you don't take any notice… I was offered that [diabetes self-management education] by the GP service, and I went, 'no thanks, I'm too busy being mad'."* [ES-T2-03]

Theme 2: Mood influences diabetes self-management

Most of the participants with severe mental illness and diabetes described the fluctuating moods they experienced as part of daily life, distinguishing these from the more extreme symptoms that occur during a relapse. Feelings of low mood, depression, stress or anxiety, which several participants linked with worrying about diabetes, were reported by many participants (including several family members and staff) to derail participants' attempts to manage their diabetes through exercise and diet, leading to lethargy and lack of motivation, and, frequently, comfort eating. One family member noted, for instance, that when her mother is *"frustrated or angry or just not feeling 100%, she won't be disciplined, especially with diet"* [ES-T3-08, family member]; similarly, a GP had observed people with severe mental illness *"who, when their mental health deteriorates, their eating deteriorates, so they may start to comfort eat… and so they lose their diabetic control"* [ES-PC-05].

More extreme declines in mood were described by several participants to engender a sense of abject helplessness where any inclination to manage diabetes could dissipate entirely:

> *"When I'm depressed … you stop caring, it's like if you stop caring about yourself, or what happens to you, it's very difficult then, for someone to say, well you need to stop eating these … you get home and you just think fish and chips. It's very, very difficult."* [ES-G2-01, person with bipolar disorder]

Several participants from all three groups discussed how both conditions could affect mood, and described the impact that low mood or anxiety could have on both conditions. However, very few participants, including staff, talked about managing mood as a priority, even though, as one psychiatrist explained, the consequences could be significant: *"six months down the line and they're acutely psychotic … their blood sugars are all over the place … then you've given yourself two big problems to manage, what would have been one small problem"* [ES-T2-12].

Theme 3: Cumulative burden of managing multiple physical conditions

Problems relating to mental health were often not the only challenge to diabetes management. Nearly all of the participants with severe mental illness and diabetes reported additional health problems such as chronic obstructive pulmonary disease (COPD), asthma, cardiovascular disease, obesity, musculoskeletal problems, sleep problems or pain. Participants from all three groups described two common ways in which this impacted on diabetes management. First, by limiting their ability to engage in physical activity or leave the house to see others or attend appointments: *"well I've got my knee that's difficult for a start off … It stops me from doing a lot of walking what I used to like doing"* [ES-T2-04, person with schizophrenia].

The second challenge was deciding which condition to prioritise, and several participants pointed out that the invisibility and perceived lack of immediate consequences of diabetes could mean that, like severe mental illness, physical health conditions that more obviously affected daily life received greater attention. As one psychiatrist noted, *"so [if] somebody has daily pain, that pain is going to take more attention than the diabetes which isn't causing any immediate pain but is a long-term complication and consequence. It's a silent killer."* [ES-T2-12]. Similarly, a woman with schizophrenia observed, *"it's a funny one, diabetes. I mean you just don't know until it's too late how it's affecting you."* [ES-T2-16].

Having multiple health problems was also reported by several participants with severe mental illness and diabetes as impacting their mood as well (see Theme 2), as one woman with schizophrenia explained, *"If I am in pain with my arthritis or I get a lot of nausea through my IBS it does affect my mood and my mental health state."* [ES-T2-05].

Theme 4: Interacting conditions and overlapping symptoms

Many, but not all participants across the three groups reported an overlap in severe mental illness and diabetes symptoms, and several participants (including staff) noted that it could be difficult to identify the underlying cause of symptoms such as fatigue, low mood, agitation or anxiety: *"I've noticed there's quite an overlap between feeling mentally low and feeling unwell because your blood sugar is up."* [ES-G8-01, person with bipolar disorder and T1 diabetes]. Several staff participants observed that fluctuating levels of blood glucose could manifest as symptoms which could be readily misinterpreted as psychological symptoms and *"give rise to symptoms which are synonymous with anxiety and low mood"* [ES-T1-01, psychiatrist]; or lead to people becoming more *"aggressive, argumentative… That's often a sign that they're not managing* (diabetes) *properly and it might not just be a sign of their mental health deteriorating."* [ES-T1-02, community mental health nurse].

The overlapping nature of symptoms was occasionally reported to have implications for diabetes management, as one participant explained, *"if I go on a high, sometimes, they've got to check my*

blood sugars, because they don't know if it's the blood sugars that are causing me to go a bit loopy. Or it's my mental illness." [ES-T4-10, person with bipolar disorder]. This led a few participants with severe mental illness and diabetes to question why they didn't receive more regular diabetes checks:

> "In diabetes what you're missing is the physiological feedback and a consultation can, to a degree, give you some of the feedback, even if it's only three times a year … Because you can lose the plot over the course of a year, whereas I think if you have a horizon of four months, that gives you an end point in sight." [ES-G8-01, person with bipolar disorder and T1 diabetes]

However, there were divided opinions and some uncertainty about the exact relationship between severe mental illness and diabetes, with most participants across the three groups describing the conditions as interacting, while a few participants with severe mental illness and diabetes saw no link and several (including staff) described a "*direct correlation*" [ES-G2-01, person with bipolar disorder] or even a causal pathway: "*anxiety makes* [blood sugar levels] *go up as well*" [ES-T3-03, person with bipolar disorder]. As one staff participant noted, this uncertainty could potentially lead to misdiagnosis: *"sometimes, the irritability that comes with a low blood sugar could be interpreted as part of somebody's mental illness. And it's diagnosed and mistreated."* [ES-T5-03, nurse]. Linked to this, some staff identified a training need:

> "I think I wasn't quite as aware as perhaps I should have been about the impact that medications do have on the patient's weight, especially weight management aims […] if you weren't aware of the significance of that medication you probably would just assume that they perhaps were […] withholding things from you." [ES-T6-02, dietitian]

Many participants in all groups perceived a relationship between the adverse effects of medications prescribed for severe mental illness and the development and management of diabetes. Commonly reported adverse effects were increased hunger, lethargy and weight gain, which were reported to impact on people's motivation, mood and capacity to live healthily and manage their diabetes. As one participant explained, "*I'm not really a greedy person but when you get the hunger from the tablets … you can't ignore it."* [ES-T2-16, person with schizophrenia].

Theme 5: Support for everyday challenges

Many participants across the study sample highlighted the central role of family members, friends or healthcare staff in providing practical or emotional support for the everyday challenges that impact on diabetes management. Several people with severe mental illness talked about the importance of having someone to accompany them shopping, to appointments, for exercise or to a café while

others valued help at home, for example with finances, cooking or organising medications. Talking to friends, other people with mental health problems or a known professional helped some participants too. For a few participants, engaging in social activities such as visiting a day centre or place of worship could provide *"another motivation (to) carry on"* [ES-G9-01, person with schizophrenia]. For several participants with good family support, the supporting family member could also act as a sentinel, watching for symptoms to emerge, *"my daughter is the one, she can tell by my voice when I'm not right."* [ES-T3-04, person with bipolar disorder].

Although in most cases this type of care was provided by a family member or mental health care co-ordinator, a few participants with severe mental illness and diabetes expressed a desire for more intensive support, for example assistance with budgeting, dietary planning and exercise regimes: *"It should be a lot more help. Not just from GPs and nurses but there should be teams going out into communities and people what are really overweight and really obese, they should be sitting them down and going over a budget plan and a plan to lose weight."* [ES-G3-01, person with schizophrenia].

However, despite the value placed on this type of support, many participants with severe mental illness and diabetes did not feel well supported. Several had lost informal support due to a breakdown in relationships, not feeling able to talk to others, or the illness or death of a family member. Staff occasionally highlighted potentially negative effects of informal support, citing examples of family members encouraging unhealthy behaviours or not understanding mental illness, and identified a need for education for those in a supporting role.

A lack of continuity of care was identified by several participants across the groups as a key barrier to accessing personalised support from healthcare staff: *"there is a lot of difference between somebody knowing you and just seeing different people each time."* [ES-D1-02, family member]. Perceptions among some people with severe mental illness and their family members that healthcare staff's time was limited and their roles prescribed were also barriers to them seeking support, and could lead to them using physical and mental health services according to the traditional divide between them. For example, one participant would not discuss her paranoia with a GP *"because it would take up an hour of a GP's time, and that's not fair, not fair on the GP and not fair on the other patients."* [ES-T2-16, person with schizophrenia]. This division was also acknowledged by several staff participants from primary care, *"our annual [diabetes] review it isn't really to do with the mental illness"* [ES-PC-01, GP], and mental health services, *"they don't tend to ask about it [diabetes] because they don't see it as part of a mental health nurse's role"* [Staff ES-T1-02, mental health nurse].

Discussion

Summary of key findings

This qualitative study provides important insights into how comorbid severe mental illness and diabetes is experienced. This often occurs in the context of multiple other health conditions and against the backdrop of additional challenges relating to employment and social support. Notably, the complex interaction between the two conditions highlights the important role of mood and of severe mental illness medications in diabetes self-management, the difficulties of differentiating between overlapping symptoms, the limited or variable prioritisation of diabetes care and management within the context of severe mental illness and other comorbidities, and the barriers to accessing support for everyday challenges.

What this study adds

This study adds to growing evidence that diabetes management is overshadowed by the many competing mental and physical health needs experienced by people with severe mental illness, which when experienced together can be overwhelmingly pervasive [10, 21, 24, 25, S36]. By including the perspectives of people living with severe mental illness and diabetes, family members and healthcare staff who support them, this study offers new insights. It confirms that diagnostic overshadowing – the attribution of physical symptoms to coexisting mental illness, leading to under-recognition of physical conditions such as type 2 diabetes [S37] – extends beyond the diagnostic period and affects diabetes management. The study also suggests that the separation of diabetes and mental health care, and the difficulties people experience in distinguishing between certain mental illness and diabetes symptoms both contribute to the overshadowing of diabetes. The latter is not commonly reported as a barrier to diabetes self-management [S38], but in the context of severe mental illness can contribute to diabetes being continually deprioritised until more distinguishable symptoms, changes in treatment, complications or related conditions occur, leading to increased morbidity and mortality [14].

The persistent and fluctuating nature of depression and anxiety among the people with severe mental illness and diabetes in this study, which impacted on their capacity and motivation for diabetes self-management, offers another potential explanation for the poor outcomes in this population. Research consistently shows that co-morbid depression increases the risk of mortality in people with diabetes [S39], and presents challenges for diabetes self-management [S40]. While depressive symptoms are common in people with severe mental illness [S41], they are often overlooked in the literature about co-morbid diabetes, which tends to focus on psychotic symptoms

and their treatment. This study suggests that, like diabetes, depression and anxiety may also be overlooked in practice because of the focus on managing and preventing psychotic symptoms.

Study strengths and limitations

Robust qualitative methods, aided by extensive patient and public involvement, allowed us to develop a rich, detailed understanding of how experiencing severe mental illness and diabetes alongside each other can impact on diabetes management. We gained additional insights by including people who support this population, enhancing our interpretation of study findings. However, while representing a diverse range of views and experiences, the study excluded people who were not in contact with healthcare services and people experiencing a psychotic episode. Additionally, the experiences of people with type 1 diabetes, those who were very unwell with diabetes and people from a minority ethnic group were under-represented, and our sample of family members and friends was smaller than planned. Care should therefore be taken when considering the transferability of findings to these groups, although by including participants with type 1 diabetes or diabetic complications we have importantly highlighted the similar ways in which severe mental illness impacts on diabetes management regardless of diabetes type, treatment or severity.

Implications for clinical practice and research

Approaches to tackle the systemic overshadowing of diabetes are needed to ensure that it is afforded appropriate priority in the context of severe mental illness. In particular, more intensive and tailored support is needed to help people overcome the multiple barriers to self-management, especially when their mental or physical health deteriorates. Clinical guidelines for multimorbidity provide a useful starting point [S42], recommending an individualised approach to care that takes account of how a person's conditions interact and impact on their lives. However, while these guidelines acknowledge the importance of care co-ordination, more needs to be done to tackle the traditional 'silo-working' of mental and physical health services, which in this study led people with severe mental illness and diabetes as well as healthcare staff to focus on one condition at a time.

Collaborative care models may offer some potential here, enhancing co-ordination between mental and physical health services, providing patients with personalised and more regular diabetes care, and ensuring staff have access to training and specialist knowledge which this study found was lacking. However, while this model is effective for managing depression and co-morbid long-term physical health conditions including diabetes [S43], there is very limited, albeit promising evidence about its value for co-morbidity in severe mental illness [S44].

Offering better continuity of care may also help. This was highly valued by the people with severe mental illness and diabetes in this study, and for some helped to compensate for the lack of informal support we observed in many participants. Although challenges to this were identified, including lack of time and continuity of staff, recent evidence from a large observational cohort study in England found that greater continuity in primary care for people with severe mental illness was associated with a reduction in unplanned hospital use, leading the authors to suggest that better relational continuity (i.e. seeing the same physician) may improve the management of physical health in this population [S45].

Finally, providing bespoke diabetes education for people with severe mental illness, their family members and healthcare staff may help to address the unique barriers to diabetes management this population experience, regardless of diabetes type, treatment or severity. For example, introducing strategies to manage the impact of low and fluctuating mood and the side effects of severe mental illness medication, and helping people to distinguish between overlapping mental illness and diabetes symptoms, may contribute to improvements in diabetes self-management.

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Table 1: Sampling characteristics for people with severe mental illness and diabetes

Characteristic
Demographic (age, gender, ethnicity) and geographical (deprivation, region) characteristics
Family composition and presence of family member who could provide support
Mental health and diabetes diagnoses
Diabetes medication
Diabetes symptoms and complications
Presence of other comorbidities
Whether they received treatment for severe mental illness from primary and/or secondary care
Whether they received treatment for diabetes from primary and/or secondary care

Table 2: Participant characteristics for the sample of people with diabetes and severe mental illness

ID	Primary diagnosis	Diagnosis order	Diabetes type	Self-reported duration of diabetes	Age	Gender	Ethnic group	Highest Education	Employment status
ES-D1-05	Depressive psychosis	Severe mental illness-DM	T2	28 years	69	M	White	No qualifications	Unemployed
ES-G2-01	Bipolar disorder	Severe mental illness-DM	T2	40	45	M	White	Degree	Employed
ES-G3-01	Schizophrenia	Not clear	T2	Years ago	47	M	White	No qualifications	Unemployed
ES-G4-01	Schizophrenia	Severe mental illness-DM	T2	Not sure. After breakdown.	55	M	White	GCSE/O levels	Unemployed
ES-G4-02	Bipolar disorder	Same time	T2	A few years. Same time as bipolar.	67	F	White	NVQ/OND/other	Retired
ES-G7-01	Bipolar disorder	DM-Severe mental illness	T1	Had it 40 years.	61	F	White	No qualifications	Unemployed
ES-G8-01	Bipolar disorder	Severe mental illness-DM	T1	30 years ago.	63	M	White	Degree	Retired
ES-G9-01	Schizophrenia	Severe mental illness-DM	T2	A few months ago (I think)	38	M	Asian/Asian British	GCSE/O levels	Unemployed
ES-SP-02	Bipolar disorder	Severe mental illness-DM	T2	-	49	F	Asian/Asian British	No qualifications	Unemployed
ES-T2-02	Bipolar disorder	Severe mental illness-DM	T2	18 months	63	F	White	No qualifications	Unemployed
ES-T2-03	Bipolar disorder	Not clear	T2	At least 5 years, not clear	51	M	White	Masters/PhD	Unemployed
ES-T2-04	Schizophrenia	Not clear	T2	Later on, 30s/40s (approximately 28-38 years)	68	F	Not recorded	Not recorded	Unemployed
ES-T2-05	Schizoaffective disorder	Severe mental illness-DM	T2	After mental illness	59	F	White	Masters/PhD	Retired
ES-T2-06	Bipolar disorder	Not clear	T2	Not clear. Diagnosed through regular blood tests so maybe after?	59	F	White	GCSE/O levels	Unemployed
ES-T2-07	Schizophrenia	Not clear	T2		44	M	Black/African/ Caribbean/Black British	GCSE/O levels	Unemployed

ID	Primary diagnosis	Diagnosis order	Diabetes type	Self-reported duration of diabetes	Age	Gender	Ethnic group	Highest Education	Employment status
ES-T2-09	Schizophrenia	Severe mental illness-DM	T2	9 years, during routine blood test	44	M	White	GCSE/O levels	Unemployed
ES-T2-16	Schizophrenia	Severe mental illness-DM	T2	2-3 years ago	65	F	White	Degree	Unemployed
ES-T2-18	Schizophrenia	Severe mental illness-DM	T2	Approximately 5 years. After severe mental illness	48	M	White	GCSE/O levels	Unemployed
ES-T3-03	Bipolar disorder	DM-Severe mental illness	T2	Thinks 10 years. Medication last 2-3 years.	34	F	White	NVQ/OND/other	Unemployed
ES-T3-04	Bipolar disorder	Severe mental illness-DM	T2	2 years ago	67	F	White	GCSE/O levels	Retired
ES-T3-07	Bipolar disorder	Not clear	T2	Not clear	71	F	White	GCSE/O levels	Unemployed
ES-T3-09	Schizophrenia	Not clear	T2	Not clear. Diagnosed through regular blood tests so maybe after?	37	F	White	GCSE/O levels	Unemployed
ES-T3-11	Schizophrenia	Severe mental illness-DM	T2	About 3 years. After severe mental illness.	60	M	White	GCSE/O levels	Unemployed
ES-T4-01	Schizophrenia	Not clear	T2	5-6 years	39	F	Mixed/ Multiple	A levels	Unemployed
ES-T4-02	Schizophrenia	Severe mental illness-DM	T2	2012. After severe mental illness	53	F	White	BTEC	Unemployed
ES-T4-09	Depressive psychosis	Severe mental illness-DM	T2	8 years ago	60	F	White	Degree	Unemployed
ES-T4-10	Bipolar disorder	Severe mental illness-DM	T2	3 years ago	41	M	White	No qualifications	Unemployed
ES-T4-12	Schizophrenia	Severe mental illness-DM	T2	Last year	41	F	White	GCSE/O levels	Employed: volunteer
ES-T4-13	Schizophrenia	Severe mental illness-DM	T2	A year ago	53	M	White	A levels	Unemployed
ES-T5-05	Schizophrenia	Severe mental illness-DM	T2	2005. After severe mental illness	35	M	Not recorded	GCSE/O levels	Unemployed
ES-T5-08	Schizophrenia	Severe mental illness-DM	T2	Can't remember. After severe mental illness	51	M	White	No qualifications	Unemployed

ID	Primary diagnosis	Diagnosis order	Diabetes type	Self-reported duration of diabetes	Age	Gender	Ethnic group	Highest Education	Employment status
ES-T5-09	Schizophrenia	Not clear	T2	Can't remember	61	M	Not recorded	No qualifications	Unemployed
ES-T5-10	Schizophrenia	Severe mental illness-DM	T2	Over 10 years	64	M	White	GCSE/O levels	Unemployed
ES-T5-11	Schizophrenia	Severe mental illness-DM	T2	3 years	59	M	Not recorded	Not recorded	Unemployed
ES-T6-05	Schizoaffective disorder	Same time	T2	Same time as severe mental illness (in hospital with severe mental illness)	39	F	Not recorded	A levels	Unemployed
ES-T6-07	Schizophrenia	Severe mental illness-DM	T2	About 16 years	60	M	White	No qualifications	Unemployed
ES-T7-02	Schizophrenia	Not clear	T2	Couple of months	28	M	Mixed/Multiple	Not recorded	Unemployed
ES-T7-03	Schizophrenia	Not clear	T2	Can't remember	53	M	Black/African/Caribbean/Black British	GCSE/O levels	Unemployed
ES-T7-04	Bipolar disorder	Not clear	T1	12 years ago	65	M	Black/African/Caribbean/Black British	A levels	Retired

Table 3: Characteristics for the family member sample

ID	Gender	Age	Ethnic group	Highest education	Relationship to person with diabetes and severe mental illness
ES-D1-02	F	71	White British	College certificate	Parent
ES-D1-03	F	73	White British	GCSE/O levels	Spouse
ES-T2-08	F	Not recorded	Not recorded	Not recorded	Parent
ES-T2-17	M	67	White British	Not recorded	Spouse
ES-T2-20	F	47	White British	Postgraduate qualification	Spouse
ES-T2-21	M	59	White British	Postgraduate qualification	Spouse
ES-T3-08	F	37	White British	Postgraduate qualification	Adult child
ES-T4-03	M	61	White British	Foundation degree	Spouse
ES-T5-12	F	56	White British	Bachelor's degree	Spouse

Table 4: Participant characteristics for the staff sample

ID	Role	Key training	Additional relevant experience
ES-PC-01	GP	Physical health	Some psychiatry experience
ES-PC-02	GP	Physical health	Used to be diabetes lead
ES-PC-03	Practice manager	Management	-
ES-PC-04	Practice nurse	Physical health	-
ES-PC-05	GP	Physical health	Diabetes lead
ES-PC-06	GP	Physical health	-
ES-T1-01	Psychiatrist	Mental health	Diagnosis and management of severe mental illness
ES-T1-02	Community mental health nurse	Mental health	-
ES-T1-03	Community mental health nurse	Mental health	-
ES-T1-04	Community mental health nurse	Mental health	-
ES-T1-05	Nurse prescriber/care coordinator	Mental health	Some previous training in diabetes
ES-T2-01	Mental health nurse	Mental health	Diabetes and physical healthcare
ES-T2-12	Psychiatrist	Mental and Physical	-
ES-T2-13	Pharmacist	Physical health	Training in psychiatric therapeutics
ES-T2-14	Dietitian	Physical health	Working in mental health
ES-T2-15	Psychiatrist	Mental and Physical	-
ES-T3-01	Pharmacist	Physical health	Training in psychiatric therapeutics
ES-T3-02	Community mental health nurse	Mental health	-
ES-T3-05	Psychiatrist	Mental and Physical	-
ES-T4-06	Recovery support worker	Social work	-
ES-T5-01	Mental health nurse	Mental health	-
ES-T5-02	Mental health nurse	Mental and Physical	Prescribing course
ES-T5-03	Nurse	Mental and Physical	Nurse prescriber
ES-T5-04	Mental health nurse - professional lead for nursing	Mental health	Previously ran team focused on physical health for severe mental illness
ES-T6-01	Mental health nurse	Mental health	Experience of work involving physical health for severe mental illness
ES-T6-02	Dietitian	Physical health	-
ES-T6-03	Care coordinator/psychiatric nurse	Mental health	Training in physical health
ES-T6-04	Commissioner	Management	-
ES-T7-01	Mental health nurse	Mental health	Senior practitioner for physical health
ES-X1-01	Diabetologist and endocrinologist	Physical health	-

Appendices

Appendix 1: Topic guides

Topic guide for the interviews with people with diabetes and severe mental illness

1. **Background information**
   - Demographic information: age, gender, employment status, ethnicity, level of educational attainment. Perception of neighbourhood – belonging/ safety. Relative financial situation.
   - Family and home circumstances: support networks, social activity, transport/ mobility issues.
   - Current health conditions
   - Experience of diabetes and mental illness diagnoses (e.g. initial signs, knowledge of risk, being given diagnoses)
   - Has anyone explained to you why you got diabetes? What did they tell you?
   - Why do you think you got diabetes?
   - Experience of post-diagnostic period for diabetes and mental illness (e.g. referrals, provision of education or information, medication and monitoring)

2. **Managing diabetes alongside mental illness**
   - Perception of how diabetes and mental illness affect activities of daily life: a 'good day' with mental illness and diabetes, a 'bad day' with mental illness and diabetes
   - Self-management activities for diabetes and mental illness (e.g. medication, health checks, diet, exercise)
   - Perception of barriers and facilitators to self-management
   - Involvement of relatives/ friends in the management of mental illness and diabetes
   - Perception of the impact of diabetes on mental illness and the impact of mental illness on diabetes
   - How well do you think your diabetes is managed?
   - What do you think helps you, or has helped you the most to manage your diabetes?
   - What things make it more difficult for you to manage your diabetes?
   - What problems, if any, do you experience because of your diabetes?
   - What problems, if any, do you experience because of your mental health?
   - New prompt added 21/05/18 – explore effects of sleep disturbance

3. **Experiencing healthcare**
   - Experiences of care/ interventions currently received for a) diabetes b) mental illness including who they would approach with concerns about their diabetes
   - Perceptions of barriers and facilitators to accessing care
   - Relationships/ communication with healthcare professionals in primary and secondary care
   - Perceptions of information/ education provision for a) diabetes b) mental illness
   - Connections with other organisations / support networks related to their condition.

- Thinking about the support and care you have received, what helps you or has helped you the most with your diabetes?
- Suggestions for improvements to the health care of people with severe mental illness experiencing diabetes

Topic guide for the interviews with family members and supporters of people with diabetes and severe mental illness

1. **Background information**
   - Demographic information: age, gender, employment status, ethnicity, level of educational attainment. Perception of neighbourhood – belonging/ safety. Relative financial situation.
   - Family and home circumstances (including whether they co-reside with the person with severe mental illness, social networks, mobility issues, access to transport)
   - Relationship with person living with diabetes and mental illness
   - Own health conditions/ status
   - Other caring commitments

2. **Supporting their relative/friend to manage diabetes alongside mental illness**
   - Basic formation about the diabetes and mental illness of the person they support [diagnoses, severity, treatment, care]
   - Has anyone explained to you why your [relative/friend] got diabetes? What did they tell you?
   - Why do you think they got diabetes?
   - How well do you think your [relative/friend] manages their diabetes?
   - What do you think helps your [relative/friend], or has helped them the most to manage their diabetes?
   - What things make it more difficult for them to manage their diabetes?
   - What problems, if any, do they experience because of diabetes?
   - What problems, if any, do they experience because of mental illness?
   - Perception of how diabetes impacts on mental illness and how mental illness impacts on diabetes

3. **Supporting their relative/friend to manage diabetes alongside mental illness**
   - Current caring / supportive activities for diabetes and mental illness (e.g. medication, lifestyle, healthcare)
   - Changes in their supportive role over time
   - Help received for their role (e.g. from other family, healthcare professionals, community/social groups, third sector) including who they would approach with concerns
   - Perception of how the diabetes and mental illness of the person they support affects shared activities of daily life: a 'good day' with mental illness and diabetes, a 'bad day' with mental illness and diabetes
   - Perceived impact of providing support on own life, on the relationship with the person with mental illness and diabetes and on the wider family context including financial and social impact

4. **Perceptions of healthcare**
   - Perceptions of the care their relative/friend currently receives for a) diabetes b) mental illness
   - Perceptions of barriers/facilitators to accessing care
   - Perceptions of education/ information provision for a) diabetes b) mental illness (for the person they support and themselves)
   - Relationships with health professionals and the extent to which they are included in health care decisions
   - Thinking about the support and care your [relative/friend] has received, what helps them or has helped them the most with their diabetes?
   - Suggestions for improvements to the health care of people with severe mental illness experiencing diabetes

Topic guide for the interviews with healthcare staff working with people with diabetes and severe mental illness

1. **Background information**
   - Current role/ length of service in that role
   - Professional training
   - Specific training received in supporting people with severe mental illness to prevent or manage co-existing diabetes

2. **Supporting management of diabetes alongside severe mental illness (severe mental illness)**
   - Role in supporting / monitoring people with severe mental illness to prevent diabetes
   - Role in supporting people with severe mental illness to manage diabetes (including when they become involved, interventions / care provided)
   - Working with others to support people with severe mental illness and diabetes (e.g. with colleagues / other professionals and services, referrals, signposting, looking specifically at primary & secondary care working practices)
   - Understanding of how diabetes impacts on severe mental illness, how severe mental illness impacts on diabetes and how both impact on daily living
   - Understanding of factors that impact on people's own management of a) diabetes b) severe mental illness
   - What do you think helps people with severe mental illness the most to manage their diabetes?
   - What do you think the main barriers to managing diabetes are for people with severe mental illness?
   - Why do you think people with severe mental illness are at greater risk of developing diabetes?
   - What complications do you think people with severe mental illness are most likely to have with their diabetes?

3. **Perceptions of diabetes care for people with severe mental illness**

- Perceptions of care and interventions delivered to support people with severe mental illness to prevent / manage diabetes (e.g. lifestyle advice, medication, monitoring, education, information provision)
- Perceptions of barriers/facilitators to a) providing care b) people receiving care
- Perceived training needs and gaps in training provision
- Perceived gaps in care provision
- Of the support and care available to help prevent diabetes for people with severe mental illness, which do you think has the most potential?
- Of the support and care available to help people with severe mental illness to manage their diabetes, which do you think has the most potential?
- Suggestions for improvements to diabetes care for people with severe mental illness
- Comparing needs of people with schizophrenia/ bipolar (new prompt added 24/05/18)

Appendix 2: Coding frameworks for the qualitative data

NVivo coding framework for interviews with people with diabetes and severe mental illness for the qualitative study (including a count of the number of files referencing each code/node and the number of individual references)

Demographics and context	39	803
Age	38	42
Caring responsibilities	4	11
Current medication	38	89
Diabetes type	23	24
Diagnoses	26	41
Ethnicity	36	39
Family details	29	78
Family health history	14	32
Hobbies and interests	12	24
Home and local environment	35	84
Level of education	35	46
Lifestyle	22	62
Mobility	12	20
Money and income	35	56
Past trauma	14	21
Personal history	24	76
Relationships and social network	21	34
Religious beliefs	8	24
Diabetes education, knowledge and training	38	297
Access to education and knowledge	4	5
Barriers to education and knowledge	19	36
Being offered education	6	6

Experience of education courses	17	31
Impact of education and knowledge	5	5
Knowledge of diabetes	23	59
Knowledge of diabetes management	33	92
Sources of information	31	58
Specific education needs for this group	2	5
Employment	35	137
Barriers to working and employment	9	15
Current working status	31	35
Experience of working with severe mental illness	11	32
Impact of health on employment	12	14
Past employment	25	41
Experience of diabetes	39	473
Burden of diabetes	8	17
Crisis points	2	2
Diabetes and diet	36	85
Diabetes control	35	116
Duration or timings of diagnosis and treatment	38	74
Experiences and perceptions of diabetes	10	17
Family history	22	29
First port of call for concerns	26	27
Good days and bad days	5	5
Impact of diabetes	18	35
Perceived causes	26	40
Stigma and discrimination	1	1
Symptoms and complications	18	25
Experience of mental health care	39	805
Access to care	18	39
Barriers to care	18	51
Changes to care	20	42
Current care	39	135
Experience of medication	31	122

Impact of care	14	30
Involvement in care decisions	6	17
Opinions on health care	35	127
Personal experiences of mental health care	30	141
Power dynamics	5	10
Timing of care received	6	14
Understanding of care received	6	9
Wishes for and thoughts on improvements	28	56
Worries about health care	7	12
Experience of mental illness	39	855
Behaviours associated with mental illness	6	12
Burden of mental illness	4	5
Coping mechanisms	10	19
Crisis points	20	31
Current state of mental health	31	87
Disclosing mental illness	10	28
Duration or timings of illness and treatment	38	75
Effect of outside influences	8	18
First port of call for concerns	33	41
Good days and bad days	26	39
Impact of mental illness	27	97
Not feeling in control	3	7
Others' opinions and perceptions	16	46
Perceived causes	20	33
Perceptions of mental illness	10	20
Personal experiences	18	52
Stigma and discrimination	13	24
Symptoms of mental illness	29	89
Understanding and perceptions of own illness	22	132
Experience of physical health care	39	435
Access to care	17	23
Barriers to care	18	33

Changes to care	11	16
Current care	39	106
Experience of medication	23	43
Follow-up care	2	2
Involvement in care decisions	1	2
Opinions on care	30	87
Personal experiences of physical health care	15	61
Wishes and thoughts for improvement	24	62
Having diabetes with severe mental illness	37	236
3-way interactions of diabetes, severe mental illness, health behaviours	3	9
Descriptions of interactions	30	63
Diabetes takes priority	1	4
Impact of diabetes on mental health	18	33
Impact of mental health on diabetes	23	63
Interactions between mental and physical care	19	53
Mental health takes priority	4	11
Informal support and social contact	39	361
Activity groups	5	8
Barriers to support	17	26
Current support	32	98
Experience of support groups	11	19
Experiences of charities and organisations	29	47
Impact of support	16	34
Loss of support	6	11
Rejecting support	2	4
Types of support	33	114
Other health problems	37	289
Effect on diabetes	11	15
Effects on mental health	12	18
Health worries	6	14
Medication side effects	5	9
Medications taken	17	31

Types of health problem	37	202
Other respondents	2	26
Psychosis during interview	4	23
Self-Management	39	679
Barriers to self-management	37	169
Deciding to change	9	16
Enablers of self-management	21	48
Feeling in control	5	10
Impact of self-management	12	37
Poor self-management	24	61
Self-management behaviours	38	217
Self-management success	15	28
Support for self-management	29	67
Tools for self-management	13	19
Worries about self-management	1	7
Unsure	2	2

There were 11 'parent' codes in the framework (seen in bold), shown with their associated 'child' nodes. There were also two additional codes used to identify any other respondents speaking during the interview, and where a person exhibited some psychotic symptoms during interview.

NVivo coding framework for the family member interviews for the qualitative study (including a count of the number of files referencing each code/node and the number of individual references)

Carer experiences	6	34
Carer dependence on main respondent	1	1
Carer feelings of distress	4	10
Carer opinion of medication	5	15
Carer personal experience of medication	2	3
General carer experiences	3	5
Demographics and context	9	228
Age	8	10
Caring responsibilities	8	36
Current medication	4	16
Diabetes type	1	1
Diagnoses	6	8
Ethnicity	8	8
Family details	6	7
Family health history	5	10
Hobbies and interests	5	13
Home and local environment	5	11
Level of education	7	9
Lifestyle	7	29
Mobility	3	4
Money and income	6	10
Past trauma	4	10
Personal history	6	12
Relationships and social network	9	33
Religious beliefs	0	0
Diabetes education, knowledge and training	7	34
Access to education and knowledge	2	4
Barriers to education and knowledge	2	2

Being offered education	2	2
Experience of education courses	3	5
Impact of education and knowledge	1	1
Knowledge of diabetes	3	12
Knowledge of diabetes management	2	3
Sources of information	2	3
Specific education needs for this group	2	2
Employment	8	41
Barriers to working and employment	3	11
Current working status	6	15
Experience of working with severe mental illness	2	2
Impact of health on employment	2	3
Past employment	4	10
Experience of diabetes	9	58
Burden of diabetes	3	4
Diabetes and diet	7	16
Diabetes control	5	14
Duration or timings of diagnosis and treatment	2	2
Experiences and perceptions of diabetes	2	2
Family history	3	4
First port of call for concerns	2	2
Impact of diabetes	5	6
Perceived causes	4	4
Symptoms and complications	2	4
Experience of mental health care	9	228
Access to care	9	25
Barriers to care	8	24
Changes to care	9	17
Current care	5	7
Experience of medication	8	19
Impact of care	6	7
Involvement in care decisions	7	10

Opinions on health care	8	52
Personal experiences of mental health care	5	6
Power dynamics	4	7
Timing of care received	5	5
Understanding of care received	2	2
Wishes for and thoughts on improvements	7	22
Worries about health care	7	25
Experience of mental illness	9	191
Behaviours associated with mental illness	7	26
Burden of mental illness	4	4
Coping mechanisms	3	3
Crisis points	6	15
Current state of mental health	5	7
Disclosing mental illness	1	1
Duration or timings of illness and treatment	5	9
Effect of outside influences	3	12
First port of call for concerns	4	5
Good days and bad days	6	14
Impact of mental illness	7	15
Not feeling in control	3	4
Others' opinions and perceptions	7	15
Perceived causes	3	14
Perceptions of mental illness	2	2
Personal experiences	4	11
Stigma and discrimination	4	5
Symptoms of mental illness	7	24
Experience of physical health care	9	58
Access to care	4	4
Barriers to care	4	5
Changes to care	0	0
Current care	1	1
Experience of medication	1	3

Follow-up care	2	4
Involvement in care decisions	3	3
Opinions on care	4	22
Personal experiences of physical health care	5	7
Wishes and thoughts for improvement	7	9
Having diabetes with severe mental illness	8	39
3-way interactions of diabetes, severe mental illness, health behaviours	4	11
Descriptions of interactions	4	6
Diabetes takes priority	2	3
Impact of diabetes on mental health	3	4
Impact of mental health on diabetes	3	5
Interactions between mental and physical care	5	8
Mental health takes priority	2	2
Informal support and social contact	9	106
Activity groups	0	0
Barriers to support	3	4
Current support	7	37
Experience of support groups	6	8
Experiences of charities and organisations	1	3
Impact of support	6	10
Loss of support	4	10
Rejecting support	5	6
Types of support	8	28
Other health problems	7	23
Effect on diabetes	2	2
Effects on mental health	2	2
Health worries	1	2
Medication side effects	3	6
Medications taken	2	2
Types of health problem	4	6
Other respondents	1	6
Self-Management	4	17

Barriers to self-management	2	3
Deciding to change	1	1
Enablers of self-management	3	3
Feeling in control	1	2
Impact of self-management	0	0
Poor self-management	2	4
Self-management behaviours	0	0
Self-management success	1	2
Support for self-management	2	2
Tools for self-management	0	0
Worries about self-management	0	0
Unsure	0	0

There were 13 'parent' codes in this framework (seen in bold), each shown with their associated 'child' nodes. There was also an additional code used to identify when a respondent other than the participant was speaking ('other respondents').

NVivo coding framework for the healthcare staff interviews for the qualitative study (including a count of the number of files referencing each code/node and the number of individual references)

Name	Files	References
Barriers to delivering and receiving care	30	205
Changes made to care	16	26
Changes needed to and recommendations for care and support	30	137
Demographics and context	30	252
Local area, ethnicity and socioeconomic status	22	61
Personal and health issues	2	4
Role and responsibilities	30	121
Special interest or experience	12	19
Training and career path	22	47
Diabetes education, knowledge and training	26	234
Access to education and knowledge	9	25
Barriers to education and knowledge	16	39
Education needs for this group	19	43
Education offered	13	26
Experience of education courses	8	32
Impact of education and knowledge	6	11
Knowledge of diabetes and management	15	24
Sources of information	19	34
Differences between disorders	20	21
Employment	1	1
Enablers of delivering and receiving care	25	68
Informal support	26	64
Any other informal support	6	7
Family support and interactions	26	57
Interactions between disciplines and types of care	30	175
Interactions of diabetes and severe mental illness	28	156
Descriptions of interactions	21	49
Diabetes takes priority	0	0

Impact of diabetes on mental health	16	20
Impact of mental health on diabetes	27	77
Mental health takes priority	7	10
Medication	26	90
Opinions on care	16	59
Other health problems	25	115
Care for comorbidities	11	13
Effect on diabetes	21	26
Effects on mental health	10	14
Types of health problem	25	62
Other services and care providers	17	33
People's experience of diabetes	16	43
People's experience of mental illness	18	36
People's self-management	29	391
Barriers to self-management	29	225
Enablers of self-management	19	47
Impact of self-management	7	7
Poor self-management	16	35
Self-management behaviours	8	10
Self-management success	4	4
Support for self-management	20	53
Tools for self-management	8	10
Personal and general experiences in job	16	50
Staff training and training needs	27	83
Types of care or service delivered and interactions with patients	30	235
Unsure	0	0

There were 20 'parent' codes in this framework (seen in bold), each shown with their associated 'child' nodes.