
Article:
Bellass, Susan orcid.org/0000-0001-9383-4116, Lister, Jennie Elizabeth orcid.org/0000-0002-2911-8331, Kitchen, Charlotte Emma Wray orcid.org/0000-0002-9323-0061 et al. (12 more authors) (2021) Living with diabetes alongside a severe mental illness : a qualitative exploration with people with severe mental illness, family members and healthcare staff. Diabetic Medicine. e14562. ISSN 0742-3071

https://doi.org/10.1111/dme.14562

What difference could **20 minutes** make to your patients with diabetes?

Give your patients time to act to prevent hypoglycaemia

The Dexcom G6 Continuous Glucose Monitoring (CGM) system has a predictive Urgent Low Soon alert that can warn when blood glucose levels will drop below 3.1 mmol/L within 20 minutes, prompting patients to take action before it's too late.

It's the difference between knowing you're already low and preventing a serious low.

The alert is associated with a significant reduction in hypoglycaemia without a corresponding rebound hyperglycaemia.[1,2]

68% reduction of time in hypoglycaemia[3]

72% reduction of severe hypoglycaemic events (SHE)[3*]

50% reduction of hypoglycaemic events at night[3]

#TheDexcomDifference

Dexcom G6

Learn more

*SHE defined as number of hypoglycaemic events requiring third-party assistance (with or without medical assistance). 1. Puhr S *et al.* Diabetes Technol Ther. 2019;21(4):155-158. 2. Puhr S *et al.* J Diabetes Sci Technol. 2020;14(1):83-86. 3 Heinemann L, *et al.* Lancet 2018;391:1367–1377. Dexcom, Dexcom G6, Dexcom Follow, Dexcom Share, and Dexcom CLARITY are registered trademarks of Dexcom, Inc. in the U.S. and may be in other countries. www.dexcom.com | +1.858.200.0200 | Dexcom, Inc. 6340 Sequence Drive San Diego, CA 92121 USA | MDSS GmbH Schiffgraben 41 30175 Hannover, Germany. LBL021139 Rev001.

Received: 9 September 2020 | Accepted: 24 March 2021

DOI: 10.1111/dme.14562

DIABETIC Medicine

RESEARCH: CARE DELIVERY

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

Sue Bellass[1,*] | 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[1,7,8] | Johanna Taylor[1]

[1]Department of Health Sciences, University of York, Heslington, York, UK

[2]Department of Sociology, Wentworth College, University of York, Heslington, York, UK

[3]Leeds Institute of Health Sciences, University of Leeds, Leeds, UK

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

[5]Centre for Health Economics, University of York, York, 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, UK

[7]Bradford District Care NHS Foundation Trust, Shipley, Bradford, UK

[8]Hull York Medical School, University of York, Heslington, York, UK

Correspondence
Sue Bellass, Department of Health Sciences, University of York, Heslington, York YO10 5NG, UK.
Email: s.bellass@leeds.ac.uk

Funding information
This publication presents independent research funded by the National Institute for Health Research (NIHR) Health Services and Delivery Research (HS&DR) programme (ref 15/70/26). SG, NS, SLP and RJ were also funded by the NIHR Yorkshire and Humber Applied Research Collaboration (NIHR YH-ARC), https://www.arc-yh.nihr.ac.uk/. The views expressed are those of the authors and not necessarily those of the HS&DR programme, the NHS, the NIHR or the Department of Health and Social Care.

Abstract

Aims: Diabetes is two to three 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 co-morbidity, 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: In all, 39 adults with severe mental illness and diabetes (3 with type 1 diabetes and 36 with type 2 diabetes), nine family members and 30 healthcare staff participated. Five themes were identified: (a) Severe mental illness governs everyday life including diabetes management; (b) mood influences capacity and motivation for diabetes self-management; (c) cumulative burden of managing multiple physical conditions; (d)

[*]Work carried out while at the University of York, now based at the Leeds Institute of Health Sciences.

interacting conditions and overlapping symptoms and (e) support for everyday challenges. People living with the co-morbidity 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.

KEYWORDS

bipolar and related disorders, co-morbidity, delivery of healthcare, diabetes mellitus, schizophrenia spectrum and other psychotic disorders, self management

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 co-morbidity, 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.

1 | 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 healthcare systems more difficult. Further complicating the experience of severe mental illness is the risk of developing type 2 diabetes, which is two to three 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- to 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 co-morbidity 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.

1.1 | Study aim

This qualitative study aimed to (a) explore the experiences of living with severe mental illness and diabetes and managing both conditions and (b) 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]

2 | PARTICIPANTS AND METHODS

2.1 | Sampling strategy

2.1.1 | 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]

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].

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 co-morbidities
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

2.2 | 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.

2.3 | 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.

2.4 | 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.

2.5 | 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.

2.6 | 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.

2.7 | Ethics approval

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

3 | RESULTS

In all, 78 people were interviewed; 39 people with severe mental illness and diabetes, 9 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 and 98 min (median =45), between 23 and 97 minutes (median =52) with family members and between 26 and 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 to 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

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, 30 s/40 s (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
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

(Continues)

TABLE 2 (Continued)

ID	Primary diagnosis	Diagnosis order	Diabetes type	Self-reported duration of diabetes	Age	Gender	Ethnic group	Highest Education	Employment status
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	Cannot remember. After severe mental illness	51	M	White	No qualifications	Unemployed
ES-T5-09	Schizophrenia	Not clear	T2	Cannot 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

(82%) were unemployed, although several of the retired and unemployed participants had previously been employed.

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.

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).

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.

3.1 | 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' 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 healthcare. 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

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	Dietician	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	Dietician	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	—

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].

TABLE 5 Themes, sub-themes and illustrative quotes

Theme	Sub-theme	Participant group	Illustrative participant quotation (f = female, m = male, numbers indicate age at interview)
Severe mental illness governs everyday life	Pervasiveness of severe mental illness	People with severe mental illness and diabetes	"Well I don't like going out on my own, I don't like doing anything on my own, I wait for my husband, so I'm just getting worse actually, not going out, putting myself off, not going to the shops or anything like that. I make appointments and then I cancel them, I used to have friends, but I haven't got any anymore, they've all deserted me." [ES-G7-01, T1]
		Family members	"If her attention starts wandering, she has, when we had the previous cooker with the rings for the hob, she put her hand on it and it made circular marks on her hand there, that was just through attention wandering." [Family member ES-T4-03]
		Staff	"Obviously, there are lots of patients who, for motivational reasons, paranoia reasons, difficulties using public transport reasons, lots of reasons, can't contemplate the thought of going to [City] Market and doing the course." [Staff ES-T2-15]
	Foregrounding mental health	People with severe mental illness and diabetes	"the sort of GP service had tried to do a diagnosis, tried to tell me it (diabetes) was important, which was never going to have any impact, 'cause when you're mad as a hatter, you don't take any notice. They're just noise in a corner" [ES-T2-03] "Whereas, I think for somebody who's diabetic, it would be, your main focus would be on the diabetes, and you'd be trying to work out what you're going to eat, and make sure, whereas for me, I'm always worried about the mental health side, and if I am in a really bad place, I don't care anyway." [ES-G2-01] "But when you're having a real bad episode all that goes out the window. And you're not looking after yourself. You're not looking after your diabetes either. And unless somebody is really on top of it with you, you can get into a mess." [ES-T3-07] "Because you can't think clearly, that's…not being able to think clearly is hard, because then you're not applying the right tools to address your diabetic situation." [ES-T7-04, T1]
		Family members	
		Staff	"I've got another patient when her mental health deteriorates she often goes into crisis and it's often related actually to benefits and things like that so her self-harm increases, her diet increases but she does just stop taking her tablets as well just because she can't be bothered with it really, so a lack of motivation you know I don't want to be here therefore why should I bother about this because I don't care, I forget the complications because I might not be here long enough to get them." [Staff ES-PC−05] "I think it's very easy to focus on physical side of things but the mental health is just a massive side of it and I think if a patient has I think if we were more trained and more aware of the mental health of a patient I think it could probably alleviate a lot of the problems for both patients and the staff." [Staff ES-PC−04]
	Financial strain and socioeconomic impact	People with severe mental illness and Diabetes	
		Family members	"And then again, there's the financial implication of that for many people. It's very difficult. And also many guys live on their own they don't care. They don't know how to cook a healthy meal, put together something that's… They've got £20 to buy food for the week and how much can I get for this to survive?" [Family member ES-T2-08]

(Continues)

TABLE 5 (Continued)

Theme	Sub-theme	Participant group	Illustrative participant quotation (f = female, m = male, numbers indicate age at interview)
		Staff	"Oh, absolutely, oh completely, we've got another gentleman who's not diabetic but I guess he's a candidate, he's on high dose antipsychotics, his self-neglect is terrible, his diet is really poor, […] and the PIP came along quite soon after I'd met him, he'd filled the form in himself which I felt somebody should have read and thought, this man is quite unwell, we'll put an additional supporting letter in saying he's got a consultant, he's got Clozaril, you know, all kind of nitty-gritty and they cut his benefit entirely, and he rang me out of the blue one day and said, they've cancelled all my money so I'll have to hang myself now, and I was absolutely terrified thinking, oh my word, what if he does." [Staff ES-T1-04] "Yeah most definitely and I suppose I'm coming from, I suppose my patients without mental health problems are coming from a reduced socio-economic group here and the places that I work so even more so with patients with mental health they often are not in employment and are living on very very much reduced resources and when you are discussing what foods to buy and prepare often it's very difficult for them to afford a lot of what you are asking them to …" [Staff ES-PC-02]
Mood influences diabetes management	Low mood/ anxiety leads to poor decisions/ diabetes management	People with severe mental illness and diabetes	"I think definitely there is a link there in if your blood sugar is low and you feel depressed or fat or you're anxious or feeling paranoid then you want comfort and I find that in naughty foods like crisps and chocolate that are very bad because crisps are carbohydrates and they turn to sugar overnight and that's not good and then the chocolate is full of sugar." [ES-T2-05] "When you're having a bad day, you're not so bothered about having salad for tea, you might be naughty." [ES-T3-09] "You're mixed up because part of you wants to live but you want to… I mean I said when I went to Slimming World I want to lose weight, because I want to live longer. You know with diabetes you're liable for a stroke, a heart attack, **** knows what else. So if I do something right on that, maybe… But other times, no, you don't want to live. And it's that, because you don't want to live in this hell you haven't created, but your mind is doing." [ES-T3-07] "A packet of short breads, five Mars Bars, that's my diet, that's because of this anxiety that takes me through sweetness, and all sorts of things" [ES-T7-04, T1]
		Family members	"if she's stressed or frustrated or angry or just not feeling 100%, she won't be disciplined, especially with diet and what should be doing to help, I suppose control the Diabetes because it's almost like a link with food. I mean, she does try but I do notice that when she's particularly stressed, it might be, well she goes one or two ways, it's either not eating very much at all, you know, so she's not getting the correct nutrients and all the rest of it. Or, she eats things that she shouldn't be eating, then it's almost like… not that there's an excuse but she's stressed and that what she fancies at that time, so, you know, she would probably go off the sort of diet that she should be on. Or care a little bit less I suppose." [Family member ES-T3-08]
		Staff	"And especially if you're depressed, you either don't want to eat anything, or you want to eat a load of chocolate and chips and things like that, which is partly the fault of the medications that we use." [Staff ES-T3-05] "I don't think if differentiates and I think the worst of all is depression. Because somebody's proper clinically depressed and flat, they don't even eat let alone go and see the GP or even get out of bed…" [Staff ES-T5-03] "They're relapsing but they're not risky. They're like, well…just see your GP, would be the answer. In the meantime, they're not eating or they're eating chocolate for five meals a day, because it's easy and they're not sleeping anymore. Their weight is ballooning or shrinking, they're getting more physically unwell, their blood sugars are raging. That person is six months down the line and they're acutely psychotic. At that point they've got retinopathy, 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." [Staff ES-T2-12]

(Continues)

TABLE 5 (Continued)

Theme	Sub-theme	Participant group	Illustrative participant quotation (f = female, m = male, numbers indicate age at interview)
	Worries about diabetes can contribute to low mood	People with severe mental illness and diabetes	"It does affect me badly because I worry. I worry about going to bed. I worry about sleeping because I think, am I going to wake up or am I not going to wake up?" [ES-T3-03] "But I just think generally my health has gone down since…my mental health has gone down since I've had diabetes. Because it's another illness, you know, you get fed up having yet something else added." [ES-T3-04] "Oh yeah, definitely because you need to be careful what you eat, being overweight. I mean, that makes me anxious. That does upset me. And knowing that I'm Diabetic, knowing I'm overweight, I am. That upsets me and that makes my anxiety worse and that makes the hallucinations worse. There's definitely a connection." [ES-T3-09]
		Family members	"being diagnosed with Diabetes and it's another thing that she's got to think about and you know, sort of contend with. So, I do think it has affected her mental health in that it's an additional thing for her to worry about." [Family member ES-T3-08]
		Staff	"Any physical illness, any long-term chronic physical illness can affect somebody's mental health. If you are living a life where you have to constantly worry about an aspect of your physical health, whether it's pain, whether it's fatigue or whether it's diabetes, and the difficulty with diabetes sometimes is that it isn't tangible in the same way, so you either are worrying about it because you're not sure what's going on, you know that your sugars aren't quite right but you haven't got skills or the support to manage it, or you don't know it's a problem until it becomes such a big problem that you have the long-term consequences, you know? […] You know, in the context of being diagnosed with the consequence of diabetes is incredibly overwhelming and then to then think about medications and then eventually insulin, you know, it's devastating and incredibly stressful, and one stress begets another stress. So yes, those definitely are related both ways." [Staff ES-T2-12]
Cumulative burden of managing multiple physical conditions	Burden of multimorbidity	People with severe mental illness and diabetes	"My COPD only allows me to go to the bottom there, and I'm coughing and wee'ing myself and everything, and I've got to be open and truthful with him, saying that I wear nappies now, I daren't go out. I only go somewhere, where my scooter will take me." [ES-T2-02] "I've also been quite recently diagnosed with, with an inflammatory arthritis, which has made life quite difficult but that's coming into play." [ES-G8-01, T1]
		Family members	"I also think she gets quite confused, because she's got things going on, not just the Diabetes but she's got other ailments, you know, so she's got Irritable Bowel and she's got a fatty liver, there's other sort of ailments that she suffers from. And obviously, there's different diets attached to those and I think sometimes that gets a little bit overwhelming for her as well in that she knows that there's certain foods she should avoid and certain things she should and shouldn't do in respect of her Diabetes. But then also, the same could be said for the other ailments that she's got and I think sometimes it will come as a little bit overwhelming because she thinks, well, there's too many things that I've got to think about what I can and can't eat. I'm just going to ignore it, if you know what I mean." [Family member ES-T3-08]

(Continues)

TABLE 5 (Continued)

Theme	Sub-theme	Participant group	Illustrative participant quotation (f = female, m = male, numbers indicate age at interview)
		Staff	"and normally if they are diabetes tablets they are on blood pressure tablets and if they are on blood pressure tablets they are on cholesterol tablets, if they are on cholesterol tablets you know they'll be on something else so that's five tablets." [Staff ES-PC−04] "for people who have had it [diabetes] quite a long-term and a number of years unfortunately for them it may mean that they may then be susceptible for things like having strokes, cardiovascular diseases which then limit the validity then for what they were doing a couple of years ago. If they are quite elderly which means if they have had a stroke then they may not have the quality of life that they did have before because unfortunately they have had series of events, such as strokes or heart attacks and then that just further deteriorates then to access how then because they may be at home or they may not be able to get out." [Staff ES-PC−04]
Interacting conditions and overlapping symptoms	Overlapping symptoms	People with severe mental illness and diabetes	"when I was poorly […] it was trying to work out whether it was my diabetes or mental health. It was a mixture of both" [ES-T3-03] "'Cause they're so closely linked for me, I can't speak for other people, but for me it is, when one gets worse, the other one does too." [ES-G2-01]
		Family members	"No, I wouldn't say that there's any connection with them at all. I think they're separate matters. I don't think her mental health problems makes her Diabetes worse, but I don't think her Diabetes influences her mental health problems either. If there is any connection at all, basically, it's lost in the mix of what creates our personalities and what creates our physiological conditions, but I can't say there's any difference, any connection, rather." [Family member ES-T2-01]
		Staff	"when it's not managed well, when they're not taking their insulin or taking their metformin when they should. When the blood sugars are high, they become more aggressive, argumentative, that's often a sign that they're not managing it properly and it might not just be a sign of their mental health deteriorating because it could be physical cause like diabetes and it's a good thing that we have these clinics where this can be monitored a bit, you know, blood glucose." [Staff (Community Mental Health Nurse) ES-T1-01] "And on the other hand, if people are diabetic and they're not maintaining their blood sugars right, it can give rise to symptoms which are synonymous with anxiety and low mood, so there is a big interface between diabetes and mental illness." [Staff ES-T1-01] "And you know, 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." [Staff ES-T5-03] "I mean certainly when they are acutely unwell their mental health will really slide and often that can be either that their diabetes is not well controlled or and then that leads on to picking up more infections and being susceptible to things. Quite often we will see them acutely because of a behavioural change that has happened as a result of an acute infection that has usually happened as a result of their diabetes not being brilliantly controlled." [Staff ES-PC−06]
	Severe mental illness medication as a barrier to diabetes management	People with severe mental illness and diabetes	"Yeah. The one I'm on at the moment, the Aripiprazole, doesn't put…well, it does put a bit of weight on me, but the Metformin takes it off again. So I'm fairly okay with my weight. But Doctor [GP] has said anything else will put weight on me. Because it gives you an appetite, it just suppresses your feeling of being full. They all do, all the antipsychotic drugs do. And that's a problem, that is a big problem. Because I'm not really a greedy person but when you get the hunger from the tablets, it is…you can't ignore it." [ES-T2-16] "when I went on psychotic medication, I put four stone on in about six months. I were only about nine stone and I went up to, at one stage, 14." [ES-T3-04]

(Continues)

TABLE 5 (Continued)

Theme	Sub-theme	Participant group	Illustrative participant quotation (f = female, m = male, numbers indicate age at interview)
		Family members	"you know, that's keeping him reasonably fit except that the diabetes and the drugs – all the drugs say that they're likely to put the blood sugar up and as a result of taking the antipsychotics and the antidepressants or whatever the other one is – he takes metformin to keep the sugar down." [Family member ES-D1-02]
		Staff	"On the flip side, the patient can begin as not diabetic, but is known to the services for a long time with severe and enduring mental illness and is on a range of antipsychotic medication, which then gives rise to… not, as such, direct weight gain, but an increase in diet, an increase in weight. Then, at some point, they can develop diabetes or poor blood sugar control, and that happens quite commonly. We call it Metabolic syndrome." [Staff ES-T1-01]
			"I think the difficulties that have been experienced often is that because of the mental health medication they are on they have got a very big appetite so they end up eating the wrong foods." [Staff ES-T1-03]
Support for everyday challenges	Family, friends and others for illness-management support	People with severe mental illness and diabetes	"Who helps me the most in continuing to be here at all? 'Cause there've been occasions when that's definitely been a possibility not to be true. My wife. So my unpaid carer, a 24 hour a day, unpaid carer, is the most critical person in my care" [ES-T2-03]
			"I don't really have a lot of friends. […] I have one friend who goes to MIND and I see him sort of once a month, once every couple of months, something like that. And really apart from that I don't really see people from one week to the next." [ES-T2-06]
		Family members	"It's easier having both of us having to watch our diet. If I munch away at huge bits of cake and he'd have to watch me, that would be awful" [Family member ES-D1-02, F, 71]
		Staff	"No man is an island, as the saying goes, and family is so important in helping to prop somebody up when they're struggling and if they are lacking in the understanding, both from the physical perspective but also from the emotional perspective, it makes it so much harder for the patient because the people who are immediately around them don't get it." [Staff ES-T2-12]
	Not all support is positive	People with severe mental illness and diabetes	
		Family members	
		Staff	"Some people, some family members are not particularly helpful and they don't understand the illness. They often think that the person involved is being lazy or difficult and they should do this, that and the other, and they won't do this, that and the other, and they believe that is just because they're being awkward. So if they come to the clinic, then you have to sort of gently try and explain that this could be part of the actual illness, not a choice to be awkward" [Staff ES-T3-05]
			"Obviously liaising with their family as well, because lots of the family bring in chocolate and full sugar coke and loads of biscuits and so on. […] Or bring tobacco, and they just bring all sorts of things that aren't going to help anyone with diabetes." [Staff ES-T5-01]
	Informal supporters needs and experiences	People with severe mental illness and diabetes	"Really lonely, really. I've been let down by so many people that I'm wary in making contact." [ES-T2-06]

(Continues)

TABLE 5 (Continued)

Theme	Sub-theme	Participant group	Illustrative participant quotation (f = female, m = male, numbers indicate age at interview)
		Family members	"I think she runs the risk and probably does to an extent become a recluse. It's very easy for her to be reclusive. That will have a knock-on effect on me because if my wife's reclusive then…I don't really like to leave her for great long periods, although I have done." [Family member ES-T2-17] "It was very, very hard. There were times, even though you know someone's ill, whether they threaten to kill you, which she did, is a very challenge to your relationship, isn't it?" [Family member ES-T2-21] "But, you know, when you've got somebody who's swearing blind that there are attackers around the corner and they're coming. You know, to wait another hour for somebody to come back to you on the phone, is a nightmare. An absolute nightmare. I was waiting and waiting for a phone call back trying to calm him down, trying to stop him going out and sort of trying to meet his attackers or whatever, you know, with a knife in hand or whatever. You just don't know what to do and you're absolutely terrified for hours. And that shouldn't happen, really." [Family member ES-D1-02]
		Staff	"You could have a very switched on family member who wants to encourage their loved one to eat healthily but I think it is more likely that that family member will just buy the person what they want to eat, if they're the one buying the food or they eat the same food and if you've got somebody who hasn't got mental health problems and isn't Diabetic, who are going to eat certain foods and if that person eats pie and chips and a packet of biscuits for their dinner at night, then that's what their person with mental health issues and Diabetes is also going to eat." [Staff ES-T5-03]
	The value of care that takes the whole person into account	People with severe mental illness and diabetes	(talking about the nurse) "Yeah she was great, she was absolutely fantastic. She could tell…when we said hello to each other she could tell my mood straight away… she asked me in depth about the problems, the real problems and what was at the back of them. Sometimes she would recommend some medication to the psychiatrist. And that was a big help. I knew she cared. I knew she was listening, because there was a follow-up" [ES-D1-05] Yeah, she was great. She was an ex-policewoman. She was absolutely fantastic. She could tell… When we said hello to each other she could tell my mood straight away. And she would speak to the psychiatrist before I got to the room, and probably brief him. […] She asked me in depth about the problems, the real problems and what was at the back of them. Sometimes she would recommend some medication to the psychiatrist. And that was a big help. I knew she cared. I knew she was listening, because there was a follow-up so to speak. [ES-D1-05] [about psychiatric nurse] "Well she says things like what do I want to do, what would I like to do, make sure my tablets are the right ones that I'm taking and then I get some vitamins, I don't know what she is, she's not a social worker, she's a nurse, a hell of a nurse but she comes to the house about once a fortnight and she'll take me out for a coffee. So, we go out in her car and we'll go for a coffee, which isn't far." [ES-G7-01, T1] "I didn't always want to in the first 2 or 3 or 4 years discuss all my feelings with my husband and if I was suicidal I wouldn't want to necessarily tell him that because I wouldn't want to frighten or worry him but I could share that and I would share that with my CPN's." [ES-T2-05] "The GP's been very supportive, I think that's been just amazing, from first getting diagnosed with diabetes, and first getting proper support for depression, they've been outstanding. And I think probably are the reason why I'm alive to be honest, because I think, one or the other would probably have killed me, if I hadn't have changed, to some extent." [ES-G2-01]

(Continues)

TABLE 5 (Continued)

Theme	Sub-theme	Participant group	Illustrative participant quotation (f = female, m = male, numbers indicate age at interview)
		Family members	"We've got a whole team of doctors down here – you never get to see the same one twice but, you used to just have one face GP you knew really well […] There is a lot of difference between somebody knowing you and just seeing different people each time. If you want to speak to a particular person you have to make an appointment. It can take a week or fortnight, you know. it depends on their schedule." [Family member ES-D1-02]
			"Because when you go to your doctor you've got ten minutes, and that's what the problem is. Many of the guys, by the time they're reaching the stage like you're talking, guys with diabetes, they've got lots of things going on with them. And they're trying to tell the doctor and it becomes like… So the doctor doesn't give them…he just says come for your annual diabetes check, come for your tablet, we have to check your liver and your kidneys. We'll do that once a year." [Family member ES-T2-08]
		Staff	"if they work better in ten minute bursts I can see them like that, if they work better as, yeah, doing something a bit more involved and if they're going to engage bet… I had a service user before that he wouldn't really sit in a room and have a chat with me, but if we cooked a meal together he'd talk about everything. So, our sessions would be less often, so I'd see him like once a month, but we'd make a meal and talk while we were cooking together, sit down, eat the meal together, and all that time we're having conversations." [Staff ES-T2-14]
			[discussing issues with PIP] "Almost all of my patients are going through that, and even if they've got a lot of physical health problems as well, and lots of specialists involved, the GPs charge for doing those reports. Which, I'm sure they have to, but that's the thing. So, they can't get reports from GPs, we, obviously, do them for free, and I will do my utmost to try and… You know, almost all of my patients, I know without hesitation they should be getting these benefits, and I don't have any qualms in writing increasingly angry letters explaining that, talking about the injustices of the system. And, I do that, not because I want to be difficult, but because I'm trying to advocate for my patients." [Staff ES-T2-15]
	The separation of mental and physical healthcare	People with severe mental illness and diabetes	"Their focus is on diabetes, yeah. Whenever I do anything that's specifically for diabetes, obviously, on the blood tests through the GP, and the results go through the diabetic nurse at the GP's surgery, but when I go for the eye test and things like that, they never ask me about mental health problems, it's never considered." [ES-G2-01]
			"But, if I've broken a leg, and I was in recovery, and I had angina, and I was being looked after, and had diabetes and being looked after, then all of that would be under one, under the GP. But psychiatry it isn't, and it's not joined up" [ES-T2-03]
			"I'm seeing my GP this Wednesday with physical [laugh] things. And the two will interact but I can't go and sit in a GP's surgery and go on about my paranoia because it would take up an hour of a GP's time and that's not fair, not fair on the GP, not fair on the other patients. So I don't do that." [ES-T2-16]
			"But the mental health team seem to understand it all round, that it is a big picture, that it is the diabetes and everything, it is the anxiety, not just one thing that the doctor's trying to get out of you, they just wanted to know what one thing what's wrong with you." [ES-T3-03]
			"So, yes, my experience on the mental health side, experiences on the diabetic side, because…and that is long-term and now I've been referred to the diabetic centre, the specialist centre, I would suggest those are borne out of lack of understanding. They haven't got anybody who mediates that's in a mental health capacity there, I find that bizarre." [ES-T7-04, T1]

(Continues)

TABLE 5 (Continued)

Theme	Sub-theme	Participant group	Illustrative participant quotation (f = female, m = male, numbers indicate age at interview)
		Family members	"if psychiatry caused the diabetes, why must the GP be doing it? Why is mental health not interested enough to see what's going on…because very seldom does your GP talk to your psychiatrist. Maybe once in a while. They don't even share the same computer system" [Parent ES-T2-08]
			"Like in three minutes he'll drink three milkshakes, and then he'll vomit. And then he can't understand where it came from. And then they make us appointments with the stomach doctor. And I said the head doctor should be working on this, it's got nothing to do with the stomach doctor. It's because the psychiatrist does nothing. We're ending up at the stomach doctor, who thinks I'm stupid because do you know, with that kind of intake you should be vomiting. I do know that. I know that, but what do you want me to do about it?" [Family member ES-T2-08]
			"But now since it's out of hospital we have to get one dosette box from the GP and a separate dosette box from the psychiatry, with different medicine in it.
			"I do find that information – even though technology is a wonderful thing and should make everything easier sometimes things don't get passed on that should get passed on. Certainly, it takes ages for any decisions about medication from the psychiatrist doctor at [mental health centre] – he changes his medication. It seems to take ages until they readjust." [Family member ES-D1-02]
		Staff	"What is our role in supporting them… I think at the moment it appears that we are the only ones that are actually supporting them in managing their diabetes because I think there is very little support from secondary care in the management of Type 2 diabetes." [Staff ES-PC−02]
			"I think it's very easy to focus on the physical side of things but the mental health is just a massive side of it and… I think if we were more trained and more aware of the mental health of a patient I think it could probably alleviate a lot of the problems for both patients and the staff" [Staff (Practice Nurse) ES-PC-04]
			"the credit will probably have to go to the health care assistants that we've got who often see these patients almost week in week out, monitoring weight and blood pressures…and able to develop really really nice relationships of trust and really plugging away at the health understanding behind some of the lifestyle management with diabetes and we've had some really good successes in terms of really impressive weight loss" [ES-PC−06, GP]
			"We would have to liaise which can be really frustrating because it's not a quick answer that you get, you've got the single point of access entry into mental health and so if somebody isn't under services at the moment and you are wanting to get some information on medication review or whatever you have to go through a single point of access and they get assessed by the wellbeing team and then they get passed on to whoever they feel is most appropriate person to see them or the team and it's very long winded. It can take up to 4/6 weeks to get a simple medication review or even to get some advice sometimes which is not brilliant really. It makes it quite frustrating for the patient and for us." [Staff ES-PC-01]
			"difficult especially with GP's, it is a very difficult to get hold of GP's, it's very hard to get hold of GP's but other experience has been really positive, with other professionals it has been really positive." [Staff ES-T1-03]
			"I think that is a bit more disjointed, I think there is still very much a divide between mental and physical in particular […] people tend to very much still sit within their own branch and it's a shame because I think you become blinkered you know and you can kind of if you tap into what is available around you I think you can certainly deliver a far more holistic service." [Staff ES-T1-05]

(Continues)

TABLE 5 (Continued)

Theme	Sub-theme	Participant group	Illustrative participant quotation (f = female, m = male, numbers indicate age at interview)
			"Everyone who's involved with that has responsibility to understand both sides. The psychiatrist needs to understand the physical impact of both the condition and the treatment. The GP needs to understand the interactions between the two. Any physician, medical professional, acute hospital needs to understand that having the two together is going to make things more complicated. There isn't a uniform answer that one side fits all approach." [Staff ES-T2-12]
			"it's not tailored to people with SMI so you know the courses aren't necessarily run in places that are local to them, they are not run in a way that's kind of made in any way enticing to them. I mean for example I sent a chap on a Desmond course recently you know the Diabetes Education course and he got kicked off because they didn't like his behaviour, well you know he's a chap with schizophrenia and actually even getting him there was massive and unfortunately you know he was never going to sit there and behave like everybody else so yeah kind of getting them to access stuff is very multi layered I suppose, it's not just getting them in the door there are lots of other bits that need to happen to really make that work." [Staff ES-PC−06]

3.2 | 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].

3.3 | 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].

3.4 | 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 did not 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, dietician]

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].

3.5 | 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 healthcare 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].

4 | DISCUSSION

4.1 | Summary of key findings

This qualitative study provides important insights into how co-morbid 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 co-morbidities, and the barriers to accessing support for everyday challenges.

4.2 | 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 healthcare, 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.

4.3 | 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.

4.4 | 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.

ACKNOWLEDGEMENTS

We would like to acknowledge the contribution of the DIAMONDS VOICE Patient and Public Involvement group. The study reported here (EMERALD) is one of a suite of studies on severe mental illness and long-term physical health conditions supported by DIAMONDS VOICE. The group's involvement has been key to the success of this study. They assisted in prioritising research questions, advised on the interview topic guides, study documentation, sample recruitment and dissemination strategies, and helped to interpret research findings via co-design workshops. Their involvement has been sustained and substantial throughout the study and the research team have valued their support and enthusiasm. We would also like to thank all those with severe mental illness and diabetes, their family members and staff from the participating general practices and mental health trusts for so generously giving their time to participate in and support this project.

CONFLICT OF INTEREST

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 a 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.

ORCID

Charlotte Emma Wray Kitchen https://orcid.org/0000-0002-9323-0061

REFERENCES

1. Hardoon S, Hayes JF, Blackburn R, et al. Recording of severe mental illness in United Kingdom primary care, 2000–2010. *PLoS One*. 2013;8(12):e82365.
2. Merrick J, Merrick E. Equal treatment: closing the gap. A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems. *JPPID*. 2007. https://doi.org/10.1111/j.1741-1130.2006.00100.x
3. Phelan JC, Link BG, Tehranifar P. Social conditions as fundamental causes of health inequalities: theory, evidence, and policy implications. *J Health Soc Behav*. 2010;51(Suppl):S28-S40.
4. Royal College of Psychiatrists. *Report of the second round of the National Audit of Schizophrenia (NAS) 2014*. London, UK: Healthcare Quality Improvement Partnership; 2014.
5. Vinogradova Y, Coupland C, Hippisley-Cox J, et al. Effects of severe mental illness on survival of people with diabetes. *Br J Psychiatry*. 2010;197(4):272-277.
6. Ward M, Druss B. The epidemiology of diabetes in psychotic disorders. *Lancet Psychiatry*. 2015;2(5):431-451.
7. Stubbs B, Vancampfort D, De Hert M, Mitchell AJ. The prevalence and predictors of type two diabetes mellitus in people with schizophrenia: a systematic review and comparative meta-analysis. *Acta Psychiatr Scand*. 2015;132(2):144-157.
8. Das-Munshi J, Ashworth M, Dewey ME, et al. Type 2 diabetes mellitus in people with severe mental illness: inequalities by ethnicity and age. Cross-sectional analysis of 588 408 records from the UK. *Diabet Med*. 2017;34(7):916-924.
9. Chang C-K, Hayes RD, Perera G, et al. Life expectancy at birth for people with serious mental illness and other major disorders from a secondary mental health care case register in London. *PLoS One*. 2011;6(5):e19590.
10. De Hert M, Cohen D, Bobes J, et al. Physical illness in patients with severe mental disorders. II. Barriers to care, monitoring and treatment guidelines, plus recommendations at the system and individual level. *World Psychiatry*. 2011;10(2):138-151.
11. Brown S, Kim M, Mitchell C, Inskip H. Twenty-five year mortality of a community cohort with schizophrenia. *Br J Psychiatry*. 2010;196(2):116-121.
12. Woodhead C, Ashworth M, Schofield P, Henderson M. Patterns of physical co-/multi-morbidity among patients with serious mental illness: a London borough-based cross-sectional study. *BMC Family Practice*. 2014;15:117.
13. Osborn DPJ, Wright CA, Levy G, King MB, Deo R, Nazareth I. Relative risk of diabetes, dyslipidaemia, hypertension and the metabolic syndrome in people with severe mental illnesses: systematic review and metaanalysis. *BMC Psychiatry*. 2008;8:84.
14. Scott D, Platania-Phung C, Happell B. Quality of care for cardiovascular disease and diabetes amongst individuals with serious mental illness and those using antipsychotic medications. *J Healthc Qual*. 2012;34(5):15-21.
15. Wu C-S, Lai M-S, Gau SS-F. Complications and mortality in patients with schizophrenia and diabetes: population-based cohort study. *Br J Psychiatry*. 2015;207(5):450-457.
16. Stahl SM, Mignon L, Meyer JM. Which comes first: atypical antipsychotic treatment or cardiometabolic risk? *Acta Psychiatr Scand*. 2009;119(3):171-179.
17. Llorente MD, Urrutia V. Diabetes, psychiatric disorders, and the metabolic effects of antipsychotic medications. *Clin Diabetes*. 2006;24(1):18.
18. Rummel-Kluge C, Komossa K, Schwarz S, et al. Head-to-head comparisons of metabolic side effects of second generation antipsychotics in the treatment of schizophrenia: a systematic review and meta-analysis. *Schizophr Res*. 2010;123(2):225-233.
19. Kilbourne AM, Rofey DL, McCarthy JF, Post EP, Welsh D, Blow FC. Nutrition and exercise behavior among patients with bipolar disorder. *Bipolar Disord*. 2007;9(5):443-452.
20. Banham L, Gilbody S. Smoking cessation in severe mental illness: what works? *Addiction*. 2010;105(7):1176-1189.
21. Holt RIG. Cardiovascular disease and diabetes in people with severe mental illness: causes, consequences and pragmatic management: review. *S Afr J Diabetes Vasc Dis*. 2012;9(3):107-111.
22. Stubbs B, Williams J, Gaughran F, Craig T. How sedentary are people with psychosis? A systematic review and meta-analysis. *Schizophr Res*. 2016;171(1–3):103-109.
23. Onwumere J, Howes S, Shiers D, Gaughran F. Physical health problems in people with psychosis: the issue for informal carers. *Int J Soc Psychiatry*. 2018;64(4):381-388.
24. Mulligan K, McBain H, Lamontagne-Godwin F, et al. Barriers and enablers of type 2 diabetes self-management in people with severe mental illness. *Health Expect*. 2017;20(5):1020-1030.
25. Mulligan K, McBain H, Lamontagne-Godwin F, et al. Barriers to effective diabetes management – a survey of people with severe mental illness. *BMC Psychiatry*. 2018;18(1):165.
26. Bellass S, Taylor J, Han LU, et al. Exploring severe mental illness and diabetes: protocol for a longitudinal, observational, and qualitative mixed methods study. *JMIR Res Protoc*. 2019;8(9):13407.
27. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349-357.
28. Patton MQ. *Qualitative evaluation and research methods*. 2nd ed. Thousand Oaks, CA: SAGE Publications; 1990.
29. Public Health England. National general practice profiles. https://fingertips.phe.org.uk/profile/general-practice (accessed 24 February 2021).

30. Taylor J, Lister JE, Boehnke J, et al. The psychosocial impact of having diabetes alongside severe mental illness: comparing results from the Diabetes Attitudes, Wishes and Needs-Severe Mental Illness (DAWN-SMI) and Diabetes Attitudes, Wishes and Needs Second (DAWN2) studies. Education, Clinical Care and Lifestyle. *Diabet Med*. 2019;36:9-11.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

How to cite this article: Bellass S, Lister J, Kitchen CEW, et al. Living with diabetes alongside a severe mental illness: A qualitative exploration with people with severe mental illness, family members and healthcare staff. *Diabet Med*. 2021;00:e14562. https://doi.org/10.1111/dme.14562

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 and (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 healthcare 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 healthcare 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 healthcare 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 and 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 healthcare	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 healthcare	35	127
Personal experiences of mental healthcare	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 healthcare	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 healthcare	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 healthcare	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 healthcare	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 healthcare	8	52
Personal experiences of mental healthcare	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 healthcare	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 healthcare	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 healthcare	5	7
Wishes and thoughts for improvement	7	9

Having diabetes with severe mental illness	8	39
Three-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

Name	Files	References
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 co-morbidities	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.