Identifying determinants of diabetes risk and outcomes for people with severe mental illness: a mixed-methods study

Jennie Lister,[1] Lu Han,[1] Sue Bellass,[2] Jo Taylor,[1] Sarah L Alderson,[2] Tim Doran,[1] Simon Gilbody,[1] Catherine Hewitt,[1] Richard IG Holt,[3,4] Rowena Jacobs,[5] Charlotte EW Kitchen,[1] Stephanie L Prady,[1] John Radford,[6] Jemimah R Ride,[7] David Shiers,[8,9,10] Han-I Wang[1] and Najma Siddiqi[1,11,12*]

[1]Department of Health Sciences, University of York, York, UK
[2]Leeds Institute of Health Sciences, University of Leeds, Leeds, UK
[3]Faculty of Medicine, University of Southampton, Southampton, UK
[4]University Hospital Southampton NHS Foundation Trust, Southampton, UK
[5]Centre for Health Economics, University of York, York, UK
[6]Patient and public involvement representative, Keighley, UK
[7]Centre for Health Policy, School of Population and Global Health, University of Melbourne, Melbourne, VIC, Australia
[8]Division of Psychology and Mental Health, University of Manchester, Manchester, UK
[9]Psychosis Research Unit, Greater Manchester Mental Health NHS Foundation Trust, Manchester, UK
[10]Primary Care and Health Sciences, Keele University, Keele, UK
[11]Hull York Medical School, University of York, York, UK
[12]Bradford District Care NHS Foundation Trust, Bradford, UK

*Corresponding author najma.siddiqi@york.ac.uk

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

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Scientific summary

Determinants of diabetes risk for people with severe mental illness

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Scientific summary

In this study, we used mixed methods to identify and explore determinants of diabetes risk and outcomes for people with severe mental illness. We integrated findings from an analysis of English anonymised longitudinal medical records from primary care; qualitative interviews with people with severe mental illness, their family members and health-care professionals living in the north of England; and service user workshops. We found that people with severe mental illness and diabetes experience poorer health outcomes than, and deficiencies in some aspects of health care compared with, people with diabetes alone.

Background

The average life expectancy for people with severe mental illnesses, such as schizophrenia or bipolar disorder, is 15–20 years lower than for the general population. Diabetes contributes significantly to this inequality, being two to three times more prevalent in this population. Various risk factors have been implicated, including side effects of antipsychotics and unhealthy lifestyles, which often occur in the context of socioeconomic disadvantage and health-care inequality.

Objectives

- In people with severe mental illness: to identify which sociodemographic, illness, family history and lifestyle factors are associated with the development of diabetes.
- In people with severe mental illness and diabetes: to identify which sociodemographic, illness, family history and lifestyle factors are associated with variations in diabetes and mental health outcomes.
- In people with severe mental illness: to compare the health-care interventions and physical and mental health outcomes of people with diabetes with those of people without diabetes.
- In people with diabetes: to compare the health-care interventions and physical and mental health outcomes of people with severe mental illness with those of people without severe mental illness.
- To understand the factors that are associated with access to, and receipt of, diabetes care and to explore the experience of diabetes health care by people with severe mental illness.
- To compare diabetes care provision for people with and people without severe mental illness, and to estimate costs for these.
- To identify which health-care interventions (e.g. medication, referrals and care pathways) may be associated with better diabetes outcomes for people with severe mental illness and diabetes.

Methods

Design

Under a social inequalities framework, a concurrent triangulation mixed-methods design was used, comprising (1) a quantitative longitudinal observational study of anonymised individual patient records of adults diagnosed with severe mental illness and (2) a qualitative interview study of people with coexisting severe mental illness and diabetes, family members who support them and health-care staff involved in the care of this patient population. The mixed-methods design was underpinned by a pragmatic paradigm, which acknowledged that each data type provided a different, but complementary, view of the relationship between severe mental illness and diabetes, and that combining the two facilitated a more complete understanding.

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Quantitative longitudinal observational study

Study population

Adult patients (aged ≥ 18 years) living in England registered with a general practice contributing research-standard data to the Clinical Practice Research Datalink (GOLD version) for the study period, 1 April 2000 to 31 March 2016.

Data sets

The Clinical Practice Research Datalink is the world's largest computerised database of anonymised longitudinal medical records from primary care. Electronically linked data for individuals in the study population were obtained from the following sources: Hospital Episode Statistics data for hospital admissions, the Office for National Statistics for date of death and the Index of Multiple Deprivation for area deprivation at practice and patient level.

Variables

Lists of potential determinants of diabetes in severe mental illness, poor diabetes-related outcomes, care pathways and interventions were collated and used, together with expert consultation, to inform the selection of a priori variables for exploration.

Statistical analysis

A range of regression models was used for statistical analyses, taking account of the hierarchical structure of the data. Linear, logistic and survival regression models were developed, as appropriate, depending on the outcome variable of interest. Multilevel mixed effects were estimated to account for the correlation in the longitudinal health records of the same patient, as well as the unobserved correlation at practice level. Analyses were conducted in line with the inequalities framework, which sought to quantify the absolute and relative effect of social inequalities on quality of care and outcomes. Specifically, when sample size permitted, we stratified analyses, for example by ethnicity, and/or used deprivation and disadvantage markers, such as the Index of Multiple Deprivation, as independent variables to estimate gap or gradient effects.

Qualitative interview study

Interviews were conducted in person or over the telephone (according to participant preference), using topic guides.

Study population

Study participants were (1) adult patients (aged ≥ 18 years) of the English NHS (from the North West, and Yorkshire and the Humber) with a recorded diagnosis of severe mental illness (not currently experiencing an acute relapse) and diabetes (type 1 or type 2, excluding gestational diabetes), living in the community; (2) relatives involved in the care of a person with severe mental illness and diabetes; and (3) health-care staff (commissioners, clinicians, nurses and other staff) who worked with people with severe mental illness and diabetes. All participants were required to have the capacity to consent to participation.

Sampling

Maximum variation purposive sampling was used, informed by demographic and illness characteristics identified during the scoping of the literature and expert consultation. People with severe mental illness and diabetes were sampled from rural and urban areas, areas of wealth and deprivation, and areas with diverse communities. Family members were recruited in the same manner. Health-care staff were also sampled purposively (general practitioners, practice nurses, diabetes nurses, mental health nurses, case managers, psychiatrists and diabetologists). Recruitment continued until data saturation was reached.

Recruitment

People with severe mental illness were identified by NHS general practice and mental health service staff using practice database and caseload searches. Participating individuals with severe mental illness and diabetes were asked to identify a person who supports them, who was then approached by the research team. Relatives who were known to clinicians were also approached. Potential participants were also recruited via existing research cohorts (if they had agreed to be contacted for future research) and clinic or website advertisements. For health-care staff recruitment, lead clinicians in participating general practices and mental health services were asked to identify health-care staff with experience of providing services to this population.

Data collection

Separate semistructured interview guides for individuals with severe mental illness and diabetes, family members and health-care staff were developed in partnership with study co-investigators, patient and public involvement and the findings from the scoping of the literature. The topic guides were amended iteratively as the project progressed. Data collection took place between April and December 2018. Written or audio-recorded verbal informed consent was obtained from all participants. With participants' permission, interviews were audio-recorded, or, if participants preferred, handwritten notes were made during and following the interview.

Data analysis

Data were analysed using NVivo 11 and 12 (QSR International, Warrington, UK). The framework method was employed, which combines deductive analysis of a priori themes identified through expert consultation and scoping of the literature, with inductive analysis of themes that emerged from the data. Analysis comprised a five-stage process of scaffolding (identifying and extracting themes), indexing (labelling and sorting data to test the framework), coding (coding the data to the framework), descriptive analysis (categorising and classifying data into higher-order themes) and explanatory analysis (detecting thematic patterns and relationships). As well as examining thematic patterns across the data, deviant cases were compared to understand the variation in managing diabetes within the sample. The key steps of the analysis were conducted by at least two researchers, and emerging findings were reviewed regularly by the project team and the patient and public involvement panel.

Mixed-methods analysis

The primary method for integration was 'convergence', which involved bringing together the quantitative and qualitative results to generate a more comprehensive understanding of the comorbid relationship between severe mental illness and diabetes. Co-design workshops also formed part of this process to ensure that study findings, and the integration of these, were interpreted by service users and health-care providers in addition to the research team. The principle of transformation was used to create merged descriptive summaries, underpinned by the study's social inequalities theoretical framework.

Results

Quantitative results

The key predictors for people with severe mental illness developing diabetes were older age (odds ratio 1.17, 95% confidence interval 1.14 to 1.21), until around 60 years of age; being of South Asian (odds ratio 2.47, 95% confidence interval 1.78 to 3.42) or black ethnicity (odds ratio 1.85, 95% confidence interval 1.25 to 2.75) (compared with white ethnicity); socioeconomic deprivation (most deprived compared with least deprived fifth, odds ratio 1.86, 95% confidence interval 1.39 to 2.48), physical comorbidity versus none; and the use of atypical antipsychotics versus no antipsychotic use (odds ratio 1.39, 95% confidence interval 1.16 to 1.67).

Common predictors for worse physical health outcomes for people with severe mental illness and diabetes were older age, socioeconomic deprivation and multimorbidity.

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People with severe mental illness and diabetes had better glycaemic and blood pressure control and were more likely to receive physical health checks than people with diabetes and no severe mental illness (blood pressure: incidence rate ratio 1.03, 95% confidence interval 1.01 to 1.06; cholesterol: incidence rate ratio 1.05, 95% confidence interval 1.03 to 1.08; body mass index: incidence rate ratio 1.09, 95% confidence interval 1.06 to 1.11). Having a severe mental illness increased the likelihood of all-cause mortality (hazard ratio 1.89, 95% confidence interval 1.59 to 2.26) and depression (odds ratio 1.86, 95% confidence interval 1.63 to 2.12) in people with diabetes. The number of elective admissions for macrovascular complications was significantly lower for people with severe mental illness (incidence rate ratio 0.64, 95% confidence interval 0.47 to 0.88), whereas the rate of emergency admissions was elevated (incidence rate ratio 1.14, 95% confidence interval 0.96 to 1.36).

People with severe mental illness and diabetes incur higher health-care costs (mean difference of £2363.90 per person per year) than people with diabetes alone; these are driven mainly by increased costs of secondary care.

Qualitative results

Interviews were conducted with 39 people with comorbid severe mental illness and diabetes, nine family members and 30 health-care staff. One interview was conducted with assistance from a translator. Eight key themes were identified:

1. mental illness affects everything
2. multimorbidity and diabetes management
3. interacting conditions and overlapping symptoms
4. mood and diabetes management
5. informal support networks
6. diabetes health care
7. diabetes knowledge and education
8. person-centred care.

The data suggested that social support, diabetes knowledge and mental health state are related to diabetes management. Staff emphasised the need for additional information and training on multimorbidity. There was evidence that physical health was diagnostically overshadowed at patient, professional and systems levels. Many participants highlighted the links between antipsychotics and increased appetite, lethargy and weight gain. Sedentary lifestyles and poor mental and physical health represented barriers to effective diabetes management. Difficulties navigating health-care systems were also reported.

Mixed-methods evidence synthesis

The key topics identified were as follows:

- Diagnostic overshadowing may explain why observed high levels of general practice contacts and diabetes checks failed to improve diabetes outcomes. This paradox may reflect structural and attitudinal separation of health services for mental or physical conditions, influencing patient and professional behaviours towards prioritising concerns over psychosis rather than diabetes.
- Depression and low mood, like diabetes, were often overlooked because of patients' and health-care professionals' readiness to attribute psychological distress to psychosis. The consequence of untreated depression could be an important predictor of physical health problems in people with severe mental illness, as well as an outcome of comorbid diabetes.
- Better diabetes control, or hidden fluctuation? Fluctuations in the diabetes control of people with severe mental illness may require more frequent monitoring than the currently recommended annual diabetes check.
- The complex impacts of multimorbidity threatened to overwhelm many participants, who responded by prioritising management of their mental illness, potentially to the detriment of their diabetes.

- Participants were aware that antipsychotic medication can cause side effects that could be detrimental to their diabetes, but they resigned themselves to tolerating these to better manage their mental disorder.
- Social relationships with others, including friends and family and health-care providers, were identified as an important resource for supporting health management, and also reported as being deficient by many participants.

Limitations

Geographically, practices with large list sizes in urban areas in the south and north-west of England are over-represented in the Clinical Practice Research Datalink data set, whereas practices in the north-east are under-represented. The quantitative analyses are based on observational data; we were unable to control for unobserved confounders. The true variation in the level of diabetes control achieved may not have been observed because of the large gaps between diabetes checks. There was inconsistent quality observed in the recording of measures by general practices. Qualitative interviews were conducted only when a participant's mental illness was stable, limiting the findings to those likely to be better managing their conditions. All study findings were limited to patients who were in contact with their general practice.

Conclusions

Improving diabetes outcomes for people with severe mental illness is a high-priority area, nationally and globally. Understanding how risk factors combine to generate a high prevalence of diabetes and poor diabetes outcomes is a necessary first step in developing tailored health-care interventions to improve outcomes for people with comorbid diabetes and severe mental illness. Better prevention and management of diabetes have the potential to significantly reduce the risk of diabetes complications, deliver large cost savings for the NHS and help improve both life expectancy and healthy years lived in people with severe mental illness.

Implications for practice

This study has clarified how existing severe mental illness and diabetes care pathways and interventions need to be better integrated to deal with the challenges of multimorbidity and to improve health outcomes for this population in England. The results suggest that people with severe mental illness need regular diabetes screening, and increased, specific, targeted support to best manage their diabetes alongside their mental health. A key worker using a case management approach could support navigation of services and provide continuity of care, while increasing social capital.

Recommendations for research

Future research should focus on exploring the relationship between health checks and outcomes, between severe mental illness and other long-term physical health conditions and whether or not diabetes is a risk factor for older-age onset of psychosis. Further exploration of the effectiveness of bespoke diabetes interventions for people with severe mental illness is required.

Study registration

This study is registered as National Institute for Health Research (NIHR) Central Portfolio Management System (37024); and ClinicalTrials.gov NCT03534921.

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