Perceptions and experiences of living with coexisting type 2 diabetes and severe mental illness

a scoping review

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Perceptions and experiences of living with coexisting type 2 diabetes and severe mental illness: a scoping review

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What is already known?

- People with severe mental illness, such as schizophrenia and bipolar disorder, have a twofold higher risk of type 2 diabetes compared to the general population for a number or reasons related to genetics, treatment, illness, socio-economic factors, and lifestyle.
- The existing literature on perceptions and experiences of people living with coexisting type 2 diabetes and severe mental illness is mainly focused on the diabetes management and treatment.
- Further research focusing on the management of both conditions in everyday life is needed to improve specialized and integrated care targeting this population.

Abstract

Aims To map existing research-based knowledge of everyday life and illness management among people with coexisting type 2 diabetes and severe mental illness, and to identify study designs, aims, populations and themes.

Methods A systematic literature search was performed on 16 April 2019 using Medline, Embase, PsycINFO, Cinahl, the Cochrane Library, and the Web of Science to conduct a scoping review. Included studies were summarized with regard to the quantity of research, the study designs, aims, populations and themes

Results From 3406 records, we included 23 studies about everyday life and illness management among people with coexisting type 2 diabetes and severe mental illness. Four studies were qualitative (observations, interviews and focus groups), and 19 were quantitative (observational and interventions) and used questionnaires. Five themes emerged in the findings: (1) diet and exercise, but not other diabetes self-care activities, are consistently compromised in the target group; (2) psychiatric exacerbation diminishes diabetes self-care; (3) social support and high self-efficacy improve diabetes self-care; (4) use of healthcare services is compromised; and (5) quality of life and well-being is poor.

Conclusions The limited research into the studied population's experiences with coexisting type 2 diabetes and severe mental illness is characterized by its heterogeneity in aims and methods and a strong focus on diabetes management and treatment. Further research focusing on the management of both conditions in everyday life is needed to improve specialized and integrated care targeting the population.

Introduction

People with severe mental illness, such as schizophrenia and bipolar disorder, have a twofold higher risk of type 2 diabetes compared to the general population [1,2] as a result of a number of factors related to genetics, treatment, illness, socio-economic factors and lifestyle [3]. People with both conditions have a shorter life expectancy than those with type 2 diabetes alone or the general population [4,5]. In addition, people with type 2 diabetes and severe mental illness are at higher risk of acute diabetic complications, as compared with people with diabetes only [7]. These inequalities are caused by multiple factors. People with severe mental illness are less likely to attend diabetes-related services, including eye examination, diabetes foot checks, retinopathy screening, and lipid profile analysis [1]. They receive less diabetes education than those without severe mental illness [8]. Furthermore, their mental and physical symptoms may hamper their utilization of healthcare services and navigation of the multiple healthcare services offered [9,10]. The self-management of type 2 diabetes in everyday life is fundamental to decreasing mortality and preventing complications [11]. The management of diabetes is considered one of the most psychologically taxing among chronic conditions [12], and likewise, the self-management of mental illness in everyday life is vital to prevent mental deterioration [13]. We focused on severe mental illnesses because of their characteristic debilitating effects on everyday life, limitations in major life activities, and duration [14]. Having to cope with the management and treatment of both type 2 diabetes and severe mental illness thus exacerbates the challenges [15].

Previous research has focused on the mechanisms underlying the association between type 2 diabetes and severe mental illness [3] and the pharmacological treatment of this population [16,17]. However, to improve illness management and treatment, it is essential to understand the complexity associated with the coexistence of both conditions and the challenges that face people with type 2 diabetes and severe mental illness in their everyday lives. Few studies have examined the daily life of people with both conditions, including their illness management and treatment practices. Moreover, most research into diabetes and mental illness has focused on both type 1 and type 2 diabetes and common mental disorders, such as depression, rather than on the study of type 2 diabetes or severe mental illness specifically [18,19]. However, treatments and effective self-management practices for type 1 and type 2 diabetes differ in many aspects [20,21]. This is even more true for the treatment and duration of common mental disorders and severe mental illness, and of the psychosocial functioning of people with those disorders [14].

The research on the perceptions and experiences of living with coexisting type 2 diabetes and severe mental illness have not yet been synthesized. We see this as crucial to specializing and adapting the treatment and support of such people. The aims of this scoping review are: (1) to map the existing research-based knowledge of everyday life and illness management among people living with coexisting type 2 diabetes and severe mental illness and (2) to identify the study designs, aims, populations and themes of relevant evidence.

Methods

The procedures for this review followed the guidelines given by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement for scoping reviews [22]. The rationale of scoping reviews is usually to identify knowledge gaps, and to assess the nature and extent of research evidence [22,23]. A scoping review provides a preliminary assessment of the scope of the available research literature (i.e. its extent, focus and variety) [22,23]. Although it shares methodological characteristics with systematic reviews, such as its systematic and transparent data collection process, the objectives of scoping reviews are usually broader and more comprehensive than those of systematic reviews [22,23]. Also, scoping reviews do not usually involve a critical

appraisal of the quality of included studies, which is different from systematic reviews [22].

A review protocol was drafted using the PRISMA statement for scoping reviews [22] and was subsequently revised by all authors. The protocol is available from the first author.

Search strategy

The following databases of articles published by scientific journals were searched for reports on the perspectives of people with type 2 diabetes and severe mental illness: Medline, Embase, PsycINFO, Cinahl, the Cochrane Library, and the Web of Science. The reference lists of included articles were also searched to identify other potentially eligible publications. The Open Grey, SveMed+, and Google Scholar platforms were additionally used for the literature search.

We were interested in identifying all research published after the year 2000 that reports the results of studies exploring everyday life or illness management of people with coexisting type 2 diabetes and severe mental illness. The search strategy included the concepts described below.

Severe mental illness

Severe mental illnesses were defined as schizophrenia spectrum and other psychotic disorders, bipolar disorders, major depression, and personality disorders, similar to and inspired by severe mental illness definitions in other reviews [24,25]. We searched for the specific diagnoses as well as for overall terms for mental disorders. While only studies including people with severe mental illness were eligible for our review, the scope of the search was increased by searching for mental disorders in general, without specifying the severity. Studies in populations including both people with and without severe mental illness were included only if results could be extracted for participants with severe mental illness.

Type 2 diabetes

We searched specifically for studies including people with type 2 diabetes. Studies with populations including both type 1 and type 2 diabetes were included only if the results for participants with type 2 diabetes were extractable.

The search was operationalized as a set of terms covering patient preferences, self-management, disease management, illness behaviour, daily living, and all types of patient-reported outcomes measuring illness management, perceptions, and needs. The identification and selection of all search terms were based on relevant literature within the field. We did not search for the broad term 'diabetes control', as this would have retrieved an excessive number of irrelevant results, such as studies using only HbA_{1c} as an outcome measure.

The search strategy, eligibility, and exclusion criteria are presented in Appendix S1 and Table 1. Search strategies were adjusted according to the search mechanisms of each database.

Selection of sources

Studies were screened using Covidence software [26]. Two reviewers (S.T.R. and V.Z.) independently screened the title and abstract of every source, based on the eligibility and exclusion criteria (Table 1). Studies whose abstracts met the exclusion criteria were rejected. Afterwards, the two reviewers independently screened the full text of the remaining articles. Conflicting views were discussed with and resolved by a third author (S.M.H.A.).

Summarizing the study themes

The selected publications were summarized with regard to the quantity of the research described, its study designs, aims, populations and themes. A table was developed, providing key information on the country, aim, study design and methods, number of participants, definitions of type 2 diabetes and severe mental illness, main results, and additional comments (Appendix S2).

The themes of the qualitative studies were extracted, inspired by the thematic synthesis outlined by Thomas and Harden [27]. Each paper's research themes were coded separately by one reviewer (S.T.R.). The summaries thus created were grouped and organized into descriptive areas; S.T.R. then considered the overall areas that were explored in accordance with the objective of this review and grouped the study designs, aims, populations and themes, which were discussed with co-authors. Subsequently, S.T.R. categorized the patient-reported measures used in the quantitative and

interventional studies into themes. Detailed descriptions of study interventions and their effects were omitted as interventions *per se* were not part of the scoping focus.

The themes and sub-themes of both the qualitative and quantitative studies were compared and integrated, discussed among authors, and summarized in a descriptive synthesis.

Results

Literature search and selection of sources

The total number of records identified was 5016 [Medline, 716; Embase, 2193; Psycinfo, 541; Cochrane Library, 323; Cinahl, 369; Web of Science, 874 (Fig. 1)].

A further two studies were included as a result of searching the reference lists of the already included studies. Exploring the reasons for our search strategy's failure to identify these two studies, we found that one had actually been retrieved, but had mistakenly been excluded in the screening of titles and abstracts, probably because of its focus on comorbid anxiety [28]. The other study had probably been excluded because the abstract referred only to diabetes self-care activities as 'DM [diabetes mellitus] control' [29].

Quantity and extent of research on perspectives of people living with type 2 diabetes and severe mental illness

The inclusion criteria were met by 23 studies, all published in 2004 or later. The studies were conducted in the USA (*n* = 11), Canada (*n* = 3), Turkey (*n* = 2), the UK (*n* = 2), Taiwan (*n* = 1), Romania (*n* = 1), Japan (*n* = 1) and Spain (*n* = 1). One study covered 14 different countries (Appendix S2).

Study designs, aims and populations

Four studies were qualitative, 15 were observational and quantitative, and four were interventional and quantitative.

Qualitative studies

For the qualitative studies, interviews, focus group discussions and observations, or a combination of these, were used. One study described the philosophical approach, as it used phenomenology [30], and one employed critical ethnography as a methodology [10]. Two other studies only described their analytical approaches, as one made use of theories of behaviour change [31] and one employed thematic analysis [32]. The aims of the qualitative studies were to explore everyday experiences of diabetes self-management [10], diabetes self-care-related beliefs and practices [30,32], as well as barriers to and enablers of effective diabetes management [31] among people with type 2 diabetes and severe mental illness. In all four studies, the definition of severe mental illness involved various mental illnesses.

Quantitative studies

For the quantitative studies, whether observational or interventional, questionnaires and structured telephone interviews were used to measure various patient-reported outcomes. The aims of the included studies varied greatly and were to examine diabetes self-care activities [33,34], diabetes-related self-efficacy and self-care behaviour [35,36], diabetes distress and diabetes-related self-care [37], barriers to and enablers of diabetes self-management [38], medication-taking and diabetes-related self-care [37,39], diabetes knowledge [40], quality of life [41,42], beliefs about hypoglycaemic and antipsychotic medication and medication-taking [43,44], clinical appointment attendance [45], and the use of and access to diabetes healthcare services [46].

Of the four interventional studies, one aimed to test the effects of a lifestyle intervention among people with type 2 diabetes and schizophrenia [47], two tested the effects of a group-based psychosocial treatment among people with type 2 diabetes and various severe mental illnesses [28,29], and one aimed to test the effects of antidepressant medications among people with type 2 diabetes and major depression [48].

The questionnaires used in the included studies are listed in Table 2 [28,29,33–49]. The questionnaires were often previously validated in other populations, for example, people with diabetes; however, the included studies often did not state whether the questionnaires had been validated for the study population of interest. Only one study used questionnaire items generated from an earlier interview study on people with coexisting type 2 diabetes and severe mental illness [38].

There was great variety in study populations. The majority of observational quantitative studies (10 out of 15) compared different groups. In all but one study, people with type 2 diabetes and severe mental illness (defined as major depression, schizophrenia, or various other mental illnesses) were compared to people with type 2 diabetes but no severe mental illness [34–37,39,41,43,46,49]. One study compared people with both type 2 diabetes and severe mental illness with people having only severe mental illness [42]; in another study, groups of people with type 2 diabetes were compared with people with different severities of schizophrenia [33]. Four observational quantitative studies investigated populations of people with type 2 diabetes and severe mental illness (with the definition of severe mental illness varying among all four studies) with no comparison with other populations [38,40,44,45]. All of the studies mentioned aimed to map experiences of living with coexisting type 2 diabetes and severe mental illness, including the barriers to and enablers of diabetes self-management [38], appointment attendance [45], beliefs about hypoglycaemic and antipsychotic medications [44], and the perceived benefits of and barriers to diabetes care [40].

Of the 15 observational quantitative studies, seven examined people with major depression separately [34,36,37,39,41,46,49], and two studies examined schizophrenia separately [33,35]. Six studies examined people with various severe mental illness diagnoses together, involving schizophrenia, schizoaffective disorder, major depression, bipolar disorder, and/or personality disorder [38,40,42–45].

Only a few of the included studies investigated characteristics of non-participants. In these studies, non-participants were less likely to have a regular income [36] and had less severe psychotic symptoms [33] compared to participants. One study discussed the possibility that non-participants were less likely to take hypoglycaemic and antipsychotic medication compared to participants [44].

Research themes

From the studies we reviewed, we identified research within the following areas: diabetes self-care activities, barriers to diabetes self-care, facilitators of diabetes self-care, healthcare utilization, and quality of life and general health. The majority of studies explored the management of diabetes self-care activities and the perceived barriers to and facilitators of this among people with coexisting type 2 diabetes and severe mental illness. The themes and sub-themes are summarized in Table 3, along with the number of studies of each theme.

Theme 1: Diet and exercise, but not other diabetes self-care activities, are consistently compromised in the target group

The majority of included studies investigating diabetes self-care activities were quantitative and based on frequently used questionnaires for measuring diabetes-related behaviour, such as the Summary of Diabetes Self-Care Activities Measure (SDSCA) [29,33–35,37–40,49]. The studies focused on diet and physical activity, foot care, blood glucose testing, smoking, and taking diabetes medication.

Diet and physical exercise. Seven included studies found that people with severe mental illness were less likely to eat healthily or to be physically active than people without severe mental illness (heterogeneously defined) or mild depressive disorder/symptoms [34–37,39,41,49]. One included study reported less physical activity in people with high levels of psychotic symptoms, compared to people with low levels of psychotic symptoms, while their diets did not differ [33].

Foot care (the individual's own foot examinations). Four included studies of self-reported foot care found no differences between people with and without severe mental illness [35,37,39,49], or between people with low vs high levels of psychotic symptoms [33]. However, one study reported a lower foot check frequency among people with severe depression compared with those with milder or no depression [34].

Blood glucose testing. Comparing frequencies of self-reported blood glucose testing, two of the included studies found no differences between people with major depression and those with mild or no depression [34,39], while three others found lower frequencies of blood glucose testing among people with severe mental illness when compared with people without severe mental illness [35,37,49].

Smoking. While one study identified no differences for self-reported smoking between people with and without severe mental illness [35], another study found higher frequencies of smoking in the former group [39].

Taking diabetes medication. Two included studies reported lower frequencies of self-reported diabetes medication among people with severe mental illness [37,41], while another reported higher frequencies of self-reported diabetes medication among people with severe mental illness compared with people without severe mental illness [43].

One interventional study reported changes in self-reported diet, exercise, blood glucose testing, foot care, and smoking among people with severe mental illness and type 2 diabetes before and after group-based psychosocial treatment. The study showed no improvement in diabetes self-care activities after the intervention [29]. Another study measured self-reported diet and physical exercise among people with type 2 diabetes and schizophrenia before and after a lifestyle intervention, and showed improvement in physical activity, but not diet, after the intervention [47].

Theme 2: Psychiatric exacerbation diminishes diabetes self-care

The barriers to diabetes self-care were explored using both qualitative and quantitative methods. The focus of the qualitative studies included in this review was on the participants' everyday experience with diabetes self-management [10,32], related beliefs and practices [30], and the barriers and enablers of effective diabetes management [31]. The quantitative studies focused on attitudes towards hypoglycaemic and antipsychotic medications and medication-taking [44], knowledge of diabetes and diabetes self-care activities [40], and barriers to and enablers of diabetes management [38]. The included studies indicated that people with type 2 diabetes have similar experiences of psychological,

physical and social barriers [10,30–32], however, some additional barriers to diabetes self-management were related to severe mental illness specifically. The barriers identified are listed below.

Constant negotiations. The included studies showed that people with type 2 diabetes and severe mental illness were aware of the importance of managing diabetes in everyday life because of the risk of complications [10,31]. They expressed their interest in engaging with diabetes self-care activities, and their intention to do so, and considered such activities to be their own responsibility [10,31]; however, they described diabetes management as a constant negotiation between what they knew was optimal behaviour and highly constrained living conditions (e.g. suboptimal living arrangements, financial constraints, and stigma) [10]. A quantitative study found an association between self-reported optimal type 2 diabetes management and giving high priority to type 2 diabetes, high perceived ability to manage type 2 diabetes, and high perceived impact of diabetes self-care activities [38].

Psychiatric symptoms. Due to their psychiatric symptoms and the adverse effects of psychotropic medication, combined with an unstructured lifestyle, people with type 2 diabetes and severe mental illness were challenged by managing diabetes [30–32]. In periods with severe mental illness activity, such as hallucinations and delusions, their diabetes self-care activities were hampered [30]. One study found that good mental health was associated with optimal diabetes self-management [38].

Loss of control. One included study showed that depression was associated with a lack of motivation to seek medical care, making participants feel overwhelmed and hopeless because of their type 2 diabetes and severe mental illness [32]. In addition, some people felt a loss of control over their health outcomes when taking medications for mental health symptoms [32].

Health literacy. Low health literacy levels and not finding health information valuable were identified as important psychological barriers to diabetes self-care activities [32]. However, one study found no association between diabetes knowledge and following a healthy diet, being physically active, and blood glucose testing [40].

Medical beliefs. In a study examining the beliefs related to hypoglycaemic and antipsychotic medications and medication-taking, people with type 2 diabetes and severe mental illness reported stronger beliefs about the necessity of their hypoglycaemic medication, compared to their antipsychotic medication [44]. However, the study found no association between taking the medication and the beliefs about the necessity of antipsychotic and hypoglycaemic medication [44].

Theme 3: Social support and high self-efficacy improve diabetes self-care

The facilitators of diabetes self-care were also explored using both qualitative and quantitative methods. The focus of the qualitative studies included in this review was on the participants' everyday experiences with diabetes self-management [10,32] and the barriers to and enablers of effective diabetes management [31]. The quantitative studies focused on diabetes-related self-efficacy and diabetes self-care [35], and barriers to and enablers of diabetes management [38]. The included studies indicated the facilitators of diabetes self-care listed below.

Social support. In studies examining perceived support from the healthcare and social services system, positive experiences with those services from people with type 2 diabetes and severe mental illness were found to be a very strong predictor of optimal diabetes management [10,38]. Family, friends, and health professionals were likewise reported as important sources of support in managing diabetes [31,32,38]. One study indicated that unsupportive social environments were experienced as barriers to engagement in diabetes self-care activities because of a lack of motivation [32].

Self-efficacy. A study investigating diabetes-related self-efficacy reported lower total diabetes-related self-efficacy among people with schizophrenia and type 2 diabetes than in people with type 2 diabetes only [35]. Participants with schizophrenia and type 2 diabetes scored lower on self-efficacy subscales for nutrition, blood glucose testing, foot checks, physical exercise, and weight control than did those with type 2 diabetes only. In addition, high diabetes-related self-efficacy was associated with improved diabetes self-care behaviour among people with type 2 diabetes and schizophrenia [35].

Theme 4: Use of healthcare services is compromised

The studies that examined perceptions of the received type 2 diabetes care were mostly quantitative, with a focus on access to and use of diabetes healthcare services [46] and barriers to and enablers of effective diabetes management [38]. One quantitative study described an investigation of outpatients' appointment attendance (for primary care, specialty care, and psychiatric care) [45], while one qualitative study explored the perceptions of people with type 2 diabetes and severe mental illness regarding challenges in engaging with diabetes self-care behaviours, including received care [32].

Use of healthcare services. In one included study, the access to and use of diabetes healthcare services was compared among people with type 2 diabetes and major depression and people with type 2 diabetes only. The presence of major depression was found to be associated with more problems in accessing care, problems in getting advice from a physician, and lower likelihood of having foot checks performed by a physician [46]. Concerning the use of healthcare services, no association was found, as some were frequent users, others infrequent users [46]. One quantitative study found that the most commonly received care services among people with type 2 diabetes and severe mental illness were blood pressure-measuring and eye checks, while the least common were seeing a diabetes specialist when in hospital, developing a care plan with assistance from a professional, and seeking specialist psychological support [38].

Appointment attendance. A high level of attendance at appointments was found to be associated with high levels of self-efficacy for mental health issues, mental health functioning, diabetes knowledge, and a low level of self-reported drug abuse [45]. While one study found no association between high levels of attendance and good self-reported physical health and social support [45], another study indicated that the physical challenges and health complications of people with type 2 diabetes and severe mental illness hampered their attendance at appointments [32].

Theme 5: Quality of life and well-being is poor

Quality of life and general health among people with type 2 diabetes and severe mental illness were examined in nine quantitative studies (five observational and four interventional studies) using various measures.

Quality of life and well-being. The included studies found lower physical and mental health-related quality of life among people with type 2 diabetes and severe mental illness than among those with type 2 diabetes only [41] or with severe mental illness only [42]. Comparing the last two groups, people with type 2 diabetes reported less satisfaction with their own health than those with severe mental illness (but not with the other life themes of daily activity, family, social relations, financial, safety) [42].

Diabetes distress. One study reported that people with type 2 diabetes and major depression had significantly higher levels of diabetes distress than people without depression [36]. Another included study showed that higher diabetes distress also predicted less healthy dieting, exercise, and medication-taking [37].

Psychosocial functions. In a study of psychosocial functioning among people with type 2 diabetes and schizophrenia, people with differing levels of psychotic symptoms were compared. No association was found between the severity of psychotic symptoms and self-reported psychosocial functioning [33].

Additionally, all four interventional studies targeting people with type 2 diabetes and severe mental illness used a measure of self-reported quality of life or general health as the outcome. The same intervention of group-based psychosocial treatment was used by two studies to test its effects on self-reported psychosocial functions, functional status (role impairment in work/school, family life/home, social life), and self-reported general health [28,29]. The studies showed improvements in self-reported functional status and general health after the intervention, and the improvements were greatest among people with coexisting anxiety [28,29]. Another study tested the effects on self-reported general health of an intervention offering antidepressant therapy to people with type 2 diabetes and major depression, and showed improvements in both mental and physical health [48]. Further, one interventional study of people with type 2 diabetes and schizophrenia tested the effect of a lifestyle intervention on confidence in diabetes self-management, and the intervention was found to be effective in improving this [47].

Discussion

The present review shows the limited extent and heterogeneous nature of research involving perspectives from people with type 2 diabetes and severe mental illness. Most research-based knowledge of everyday life and illness management among people with coexisting type 2 diabetes and severe mental illness is based on quantitative studies using questionnaires. Of the 23 studies included, we identified five themes related to the perceptions and experiences of living with coexisting type 2 diabetes and severe mental illness. The studies showed that diet and exercise, but not other diabetes self-care activities, were consistently compromised in the target group. Psychiatric exacerbation diminished diabetes self-care in this population, but social support and high self-efficacy improved diabetes self-care. The use of healthcare services were compromised, and quality of life and well-being were poor among people with both conditions. This review has found diabetes management and treatment to be the predominant foci of research on people with type 2 diabetes and severe mental illness. This indicates the need for further research into integrating the study of the management of both type 2 diabetes and severe mental illness for this population. Both type 2 diabetes and severe mental illness require high levels of self-management to juggle treatment schedules in everyday life [13], and the complexity of these tasks adds to the multiple mental and physical problems faced by people with both conditions.

Many of the studies included in this review used questionnaires to measure self-reported experiences of illness management and everyday life with type 2 diabetes and severe mental illness; however, the questionnaires were often not validated in the studied population as recommended by most questionnaire validation procedures [50]. This indicates a need for further research studying what scales are fit for purpose in a population of people with coexisting type 2 diabetes and severe mental illness. In addition to this, our review indicates a strong focus of research on illness management and behaviour that has been chosen and predefined by researchers. This further indicates a need for more qualitative research into the studied population's experiences with type 2 diabetes and severe mental illness and for using qualitative methods when selecting and validating questionnaires.

In the included studies, the populations with severe mental illness included a range of people with

different disorders, such as schizophrenia, major depression, and bipolar disorder. Across and within disorders, the symptoms and their severity were also very heterogeneous [51]. Some of the studies involved separate populations of people with major depression or schizophrenia, while others had studied populations with various severe mental illnesses without distinguishing their diagnoses. Additionally, one study compared people with type 2 diabetes and major depression with people with type 2 diabetes and mild or no depression, while in other studies the comparison group consisted of people with no diagnosis. The diversity of definitions and use of comparison groups may help explain the variety within some of the studied themes.

This review provides an overview of the study designs, aims, populations and themes of research in everyday life and illness management among people with type 2 diabetes and severe mental illness, and the methods used were systematic and transparent. However, as the present review focused on studies mostly based on self-reports, we need to be aware of the risk of recall bias and information bias when interpreting the results of the quantitative studies included. The informants may have reported better performances than if an objective measure had been used [52,53]. This risk of bias was mentioned in some of the included questionnaire-based studies [37,39,43,46]. We should likewise be alert to the risk of selection bias, as the individuals who agreed to participate in the studies may have differed from those who declined participation. This type of bias may limit the generalizability of the findings to all people with type 2 diabetes and severe mental illness.

We are aware that the narrow strategy used in the search for papers on type 2 diabetes may have excluded articles solely using the term 'diabetes', with no specification of type. However, in testing the search strategy without indicating a specific diabetes type, an excessive number of search results with no relevance to our research were retrieved, supporting our specified search strategy for type 2 diabetes. We furthermore included studies of participants with type 1 and type 2 diabetes only when it was possible to extract results for participants with type 2 diabetes only. Likewise, studies recruiting people with and without severe mental illness were included only when the results for people with severe mental illness were extractable. The eligibility criteria could have excluded relevant literature, such as studies with no definition of diabetes type, which may have offered perspectives on people

with type 2 diabetes; however, to develop a rigorous and transparent search strategy, very clear and well-defined eligibility criteria were required.

Likewise, our use of a broad search strategy including search terms such as 'disease management', 'self-care', and 'health behaviour' was considered appropriate for this review, because our aim was to scope the study designs, aims, population and themes within this research field. However, it is possible that not every published study within each of the specific themes was identified in this review.

This scoping review showed that the challenges facing people whose everyday life is affected by type 2 diabetes and severe mental illness are distinct from those of people who live with either type 2 diabetes or severe mental illness only. However, the research that has been performed in this population is characterized by heterogeneity and a strong focus on the management and treatment of diabetes only. More qualitative research into the studied population's experiences with type 2 diabetes and severe mental illness is needed to understand the complexity associated with the coexistence of these conditions in everyday life. Moreover, research focusing on the management of both type 2 diabetes and severe mental illness, not type 2 diabetes only, is needed to improve the targeting of specialized and integrated care in the population. Finally, research focusing on validation procedures when using questionnaires to measure various patient-reported outcomes is needed to provide effective and valid measures fit for purpose in this population.

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Competing interests

None declared.

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FIGURE 1 Review flow chart.

Table 1 Eligibility and exclusion criteria

	Rationale/clarification	Search terms (Medline)
Studies were included if they:		
Were written in English, Danish, Norwegian or Swedish	Only articles that could be read without translation were included.	
Were conducted after year 2000	Year 2000 was chosen as a pragmatic cut off for discard of studies due to contextual differences, e.g. changes in medication and other treatment practices	
Studied people with type 2 diabetes and SMI (we included studies that recruited participants with SMI defined as schizophrenia spectrum and other psychotic disorders, bipolar disorders, major depression or personality disorders	Studies recruiting participants with type 1 and type 2 diabetes were included only if extraction of results for participants with type 2 diabetes was possible, and we included studies that recruited participants with and without SMI only if we could extract results for participants with SMI. Studies recruiting participants with major depression were included in this review if the authors of the study defined the depression as major or severe. † The SMI and type 2 diabetes	Mental Disorders/ exp depressive disorder, major/ or exp depressive disorder, treatment-resistant/ exp "schizophrenia spectrum and other psychotic disorders"/ exp "bipolar and related disorders"/ exp personality disorders/ ((mental or psychiatric) adj3 (disorder* or illness* or disease* or diagnos?s)).tw. (schizo* or psychos?s or psychotic).tw. ((bipolar or affective or personality) adj3 (disorder* or disease*)).tw. ((major or unipolar or clinical or recurrent) adj3 depress*).tw. (mania* or manic).tw. SMI.tw.

	definitions in each study are reported in Appendix S2, giving study characteristics.	exp Diabetes Mellitus, Type 2/ (MODY or NIDDM or T2D*).tw. (non insulin* depend* or noninsulin* depend* or noninsulin?depend or non insulin?depend*).tw. ((typ? 2 or typ? II or typ?2 or typ?II) adj3 diabet*).tw. (((late or adult* or matur* or slow or stable) adj3 onset) and diabet*).tw.
Included perspectives from people with type 2 diabetes and SMI about illness management, everyday living, quality of life, or experiences and preferences of treatment practices	The perspectives could be patient-reported measures studied by use of questionnaires or patient experiences or perceptions studied in qualitative studies.	exp disease management/ exp "activities of daily living"/ or exp self care/ or exp self-management/ exp Patient Preference/ exp health behavior/ or exp illness behavior/ ((patient* or user* or client* or citizen* or consumer* or person* or people) and (perspective* or preference* or view* or experience* or manag* or behavio?r* or need* or challenge* or habit* or perception* or perceive* or priorit*)).tw. (self-manag* or self care or cope or coping or everyday or daily living or daily life).tw.
Studies were excluded if they:		
Were (systematic) reviews or meta-analyses	Because they used different eligibility/exclusion criteria and included studies that were irrelevant to this review. We went through relevant (systematic) reviews or meta-analyses and included single studies if they met eligibility criteria.	

Were clinical guidelines, conference abstracts, protocols, or book chapters.	Single references in the relevant clinical guidelines, protocols or book chapters were included if they met eligibility criteria.	

SMI, severe mental illness.

We did not exclude studies on study quality, which is characteristic for scoping reviews [22].

[†]Mild-moderate depression is considered a common mental disorder, traditionally treated in the primary sector by general practitioners and psychologists. Severe depression or major depression is a disorder which require specialist psychiatric treatment, frequently with a combination of pharmacological compounds and/or combination with physical treatment like electro convulsive therapy, TMS or other. The latter type of (recurrent) depression is considered a severe mental disorder [54].

Table 2 Questionnaires used in the identified literature

Questionnaire	**Outcome measure**	**Study**
Summary of Diabetes Self-Care Activities Measure (SDSCA)	Patients' performance of diabetes self-care tasks relating to diet, exercise, blood sugar testing and foot care in the previous week.	Chen 2014 [35] Dickerson 2005 [40] Gonzalez 2007 [49] Gonzalez 2008 [37] Lin 2004 [39] Mulligan 2018 [38] Mut-Vitcu 2016 [34] Ogawa 2011 [33] Sajatovic 2017 [29]
Short-Form Health Survey (SF-36)	Self-reported general health (physical and mental)	Gunzler 2017 [45] Aftab 2018 [28] Nicolau 2013 [48] Sajatovic 2017 [29]
Global Assessment of Functioning Scale (GAF)	Global functioning of psychiatric patients	Gunzler 2017 [45] Ogawa 2011 [33] Aftab 2018 [28] Sajatovic 2017 [29]
Diabetes Knowledge Test	Diabetes knowledge	Dickerson 2005 [40] McKibbin 2006 [47] Sajatovic 2017 [29]

Problem Areas in Diabetes Scale (PAID)	Diabetes-specific distress	Gonzalez 2008 [37] Lloyd 2018 [36]
Beliefs about Medications Questionnaire: Specific version, (BMQ-Specific)	Patients' beliefs about the necessity of their medications for controlling their illnesses and their concerns about the adverse effects of taking medications.	Aakre 2012 [44] Kreyenbuhl 2011 [43]
Sheehan Disability Scale (SDS)	Functional status (role impairment in three domains; work/school, family life/home, social life)	Aftab 2018 [28] Sajatovic 2017 [29]
Psychological distress (CORE-10)	Psychological distress over the previous week.	Mulligan 2018 [38]
Diabetes UK Care Survey	Experiences of received recommended diabetes care	Mulligan 2018 [38]
No name (a questionnaire of 27 items, developed in the study)	Barriers to and enablers of diabetes self-management	Mulligan 2018 [38]
Brief Medication Questionnaire (BMQ)	Patients' adherence to their medications	Kreyenbuhl 2011 [43]
Diabetes Management Self-efficacy Scale (DMSES)	Patients' levels of confidence in managing nutrition, blood glucose testing, foot checks, physical exercise, weight control and medication treatment.	Chen 2014 [35]
Perceived Diabetes Self-Management (PDSMS)	Self-efficacy for diabetes management	Gunzler 2017 [45]
Perceived Mental Health Self-Management Scale (PMHSMS)	Self-efficacy for SMI	Gunzler 2017 [45]
Diabetes Basic Knowledge Test	Level of knowledge of diabetes	Ogawa 2011 [33]
Diabetes Health Beliefs Scales	Perceived benefits of and barriers to diabetes care	Dickerson 2005 [40]
Drug Abuse Screening Test (DAST-10)	Drug use, excluding alcohol and tobacco, in the past 12 months	Gunzler 2017 [45]

Food Frequency Questionnaire, based on Food Groups (FFQg)	Energy and nutrient intake	Ogawa 2011 [33]
Multidimensional Scale of Perceived Social Support	How patients perceive their social support system, including family, friends and others	Gunzler 2017 [45]
Brief Quality of Life Interview (QOLI)	Patients' satisfaction with their life overall and in specific domains (daily activity, family, social relations, financial, work, safety, health)	Dickerson 2008 [42]
Medical Outcomes Survey, Short-Form-12 (MOS SF-12)	Patients' perspectives of their health-related functional status (social functioning, physical health, emotional problems, perceptions of mental health, general health etc.)	Dickerson 2008 [42]
WHO QoL Assessment-Brief (WHOQOL-BRIEF)	Quality of life (domains; physical health, psychological health, social relationships, environment, and social pressure)	Eren 2008 [41]
Diabetes Empowerment Scale	Confidence in diabetes management	McKibbin 2006 [47]
Health Habits and History Questionnaire	Dietary intake	McKibbin 2006 [47]
Yale Physical Activity Scale	Physical activity	McKibbin 2006 [47]

SMI, severe mental illness.

Table 3 Study themes and sub-themes (total number of studies = 23)

Themes	Number of studies	Sub-themes
Diet and exercise, but not other diabetes self-care activities, are consistently compromised in the target group	Total: 13 Qualitative: 1 Quantitative: 10 Interventional: 2	*Diet and physical exercise:* People with type 2 diabetes and SMI were less likely to eat healthily or to be physically active than people without SMI [33–37,39,41,49]. *Diabetes foot care*: There were no differences in self-reported foot care when comparing people with and without SMI [33–35,37,39,49] *Blood glucose testing*: Lack of consistence in findings when comparing the frequencies of self-reported blood glucose testing between people with and without SMI [34,35,37,39,49]. *Smoking*: Lack of consistency in findings when comparing self-reported smoking between people with and without SMI [35,39]. *Taking diabetes medication*: Lack of consistency in findings when comparing frequencies of self-reported diabetes medication between people with and without SMI [37,41,43].
Psychiatric exacerbation diminishes diabetes self-care	Total: 7 Qualitative: 4 Quantitative: 3	*Constant negotiations:* People with type 2 diabetes and SMI described diabetes management as a constant negotiation between what they knew was optimal behaviour and highly constrained living conditions [10]. *Psychiatric symptoms:* People with type 2 diabetes and SMI were challenged by managing diabetes due to psychiatric symptoms and adverse effects from psychotropic medications [30–32,38]. *Loss of control:* People with type 2 diabetes and SMI felt loss of control and lack of motivation to seek medical care [32].

		Health literacy: Lack of consistency in findings when studying the importance of health literacy for diabetes management [32,40] *Medical beliefs:* Neither beliefs about the necessity of taking medication nor concerns about risks were associated with taking medication [44].
Social support and high self-efficacy improve diabetes self-care	Total: 5 Qualitative: 3 Quantitative: 2	*Social support:* The healthcare system, the social service system, and family and friends were important sources of support managing diabetes [10,31,32,38]. *Self-efficacy:* High diabetes-related self-efficacy was associated with improved diabetes self-care behaviour among people with type 2 diabetes and schizophrenia [35].
Use of healthcare services is compromised	Total: 4 Qualitative: 1 Quantitative: 3	*Use of healthcare services*: The presence of major depressions was associated with both increased and decreased use of healthcare services, more problems in accessing care, more problems in getting advises from a physician and lower likelihood of having foot checks performed by a physician. The most commonly received care were blood pressure-measuring and eye checks. The least common were being seen by a diabetes specialist when in hospital, developing a care plan with a professional and seeking specialist psychological support [38,46]. *Appointment attendance*: A high level of attendance at appointments was found to be associated with high levels of self-efficacy for mental health issues, mental health functioning, diabetes knowledge, and a low level of self-reported drug abuse [32,45].
Quality of life and well-being is poor	Total: 9 Quantitative: 5 Interventional: 4	*Quality of life and well-being:* People with type 2 diabetes and SMI had lower physical- and mental-health related quality of life than people with type 2 diabetes only or with SMI only [41,42].

		Diabetes distress: People with type 2 diabetes and major depression had higher levels of diabetes distress than people without depression [36,37]. *Psychosocial functions:* No association was found between the severity of psychotic symptoms and psychosocial functioning [33].

SMI, severe mental illness.

Some included studies examined more than one theme, why the sum of the numbers of studies is not 23.

Some included studies examined clinical measures, e.g. HbA_{1c}. We did not report these results in this review, because they are not patient perspectives.

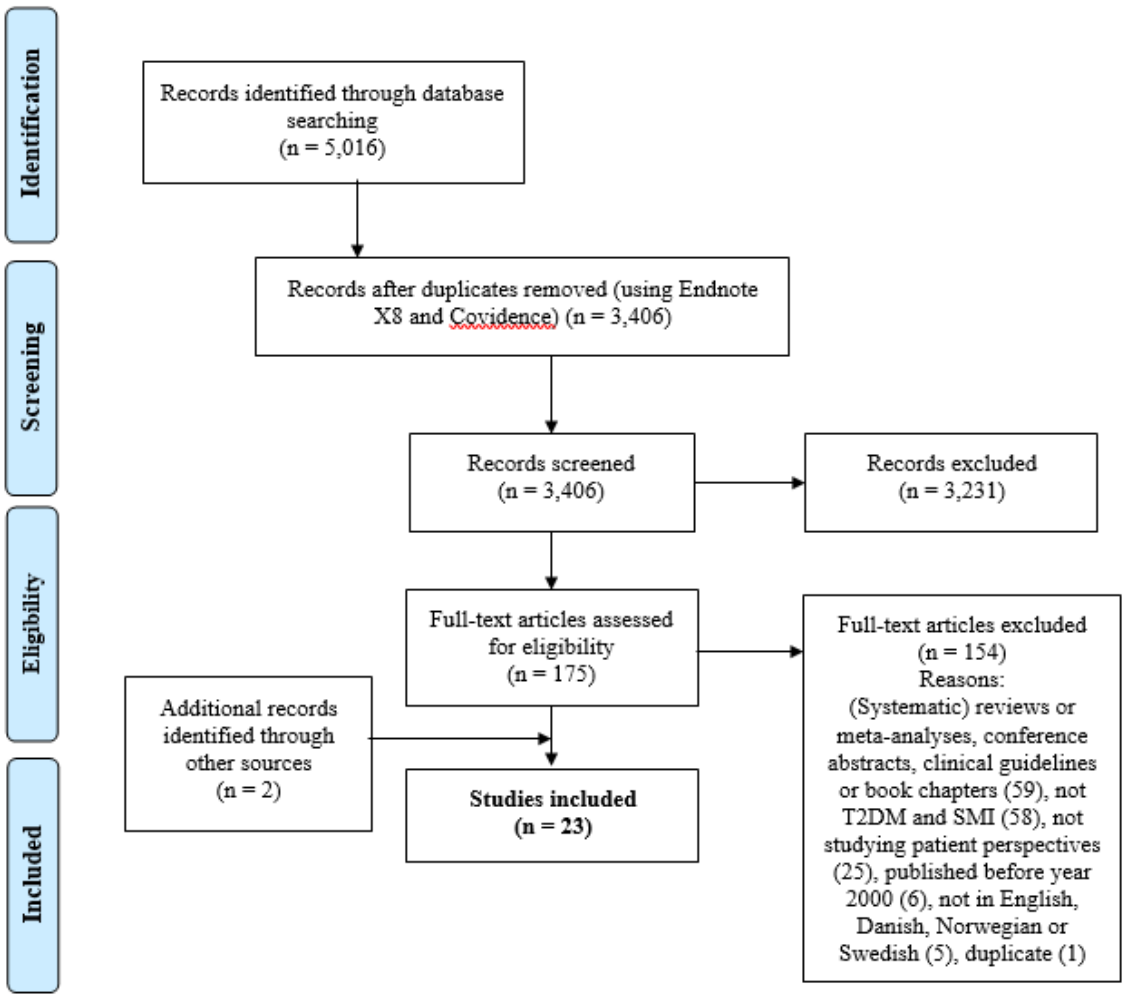
Supporting information

Additional Supporting Information may be found in the online version of this article:

Appendix S1. Example of the electronic search strategy.

Appendix S2. Table of study characteristics.

Figure 1: Flowchart



Search date for all databases: 16th of April 2019