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Interventions involving own treatment choice for people living with coexisting severe mental illness and type 1 or 2 diabetes

A scoping review

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“Interventions involving own treatment choice for people living with coexisting severe mental illness and type 1 or 2 diabetes: A scoping review”

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Conflict of interest

None to declare

Highlights

- **What is already known?**

Severe mental illness is a broad category of mental disorders like schizophrenia, schizoaffective disorders, and severe personality disorders characterized by long-term treatment needs. People with severe mental illness have a two-to four-fold higher risk of developing type 2 diabetes, and people with type 1 or 2 diabetes are at an increased risk of developing depression and other physical complications.

- **What this study has found**

When focusing on interventions involving own treatment choice for people living with coexisting diabetes and severe mental illness, it is of concern that the interventions only target one condition. This is notably in the intervention content as well as in the reported outcomes.

- **What are the clinical implications of the study?**

- Further research on interventions targeting the dual problems faced by this population is needed.

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Abstract

Aim: The objective of this scoping review was to summarize, understand, and provide an overview of the empirical literature on interventions involving own treatment choice for people with co-existing diabetes (type 1 and 2) and severe mental illness.

Methods: This scoping review, undertook a systematic literature assessment. Searches were performed in MEDLINE, Embase, PsycINFO Web of Science, Cinahl, the Cochrane Library, and in the gray literature (OpenGrey, Google Scholar, and Danish Health and Medicine Authority databases). Publications from 2000 to July 2020 were of interest. Studies were included if they involved the users' own choice of treatment. Included studies: RCT studies, intervention studies, cohort studies and cased based studies.

Results: A total of 4320 articles were screened, of which nine were included. The review identified eight studies from the U.S. and one from Canada testing different interventions for people with severe mental illness and diabetes (one diabetes education program, five randomized controlled trials, one retrospective cohort study, one naturalistic intervention program, and one case vignette). The interventions described in the nine articles involved service users, the majority incorporated individualized healthcare plans, and all interventions were based on multidisciplinary teamwork.

Conclusions: Research in the area is limited. Care management interventions tend to focus on a single condition, paradoxically excluding severe mental illness during enrollment. Interventions aimed at people with both conditions often prioritize one condition treatment leading to an unbalanced care.

Keywords: Psychiatric disorders, Type 1 diabetes, Type 2 diabetes, Combined care, Comorbid illness

Introduction

People living with severe mental illness (schizophrenia, bipolar, major depressive disorder, non-organic psychotic disorder, including schizoaffective disorder, and personality disorder), have a higher mortality rate with a shorter life-span of 10-20 years compared to the general population, often caused by physical health conditions such as diabetes (1,2). The prevalence of type 2 diabetes is high among people with severe mental illness typically due to overweight and metabolic conditions (2–5). Alongside this, being diagnosed with diabetes (type 1 or 2) increases the risk of developing a depression (6,7). People diagnosed with both type 1 and 2 diabetes and severe mental illness (SMI) experiences high or very fluctuating levels of mental distress, affecting social function and daily living (10–12). In addition, distress is often caused by the experience of stigma and the lack of recognition of both conditions in treatment and personal care preferences as people with both conditions are less likely to receive diabetes services and care support, such as diabetes education, and HbA1c testing (2,13). A literature review has highlighted the need for greater collaboration between the specialties of psychiatry and endocrinology and for physicians to rethink diabetes care practices for persons with mental illness (2). The management of coexisting chronic disorders moreover requires that individual preferences and values are addressed to tailor treatments through the use of involving the service users (14).

Involvement of service user in healthcare planning has become more widespread over the last decade as evidence-based guidelines for health promotion and illness prevention are beginning to support informed choice globally (15). Involvement of users' own treatment choice, informed by interventions inspired by shared decision-making are gaining ground when recommendations and planning of involvement of service users, preventive health risk and treatment takes place, e.g. for diabetes foot ulcers treatments based on the service user's unique background history (15,16). Furthermore, shared decision-making can improve health outcomes and promote recovery from mental health problems (17–19). Guidelines for shared decision-making describe procedures on how information is to be shared between the health professionals and the service user. The process applies decision aid tools designed to facilitate and implement shared decisions (20). The health professionals must inform the users of treatment risk, options, and benefits, while the service users share their preferences and values. (21). The guidelines recommend that treatment planning integrates elements of the person's unique background, such as their family history, personal history, and values (15). Despite such recommendations, suggestions for the physicians' engagement with personal healthcare plans in decision-making and clinical practice are scarce (15). A 2017 Cochrane review of 105 trials found that the implementation of decision aids in medical health treatment improved service users' knowledge, risk perception, and ensured better consistency

with the users' preferences and values (22,23). However, there are various definitions of ways to involve services users' own treatment choice in health care planning (e.g. user participation as a cooperation to understand information, or the patient as partner) to improve healthcare outcomes and enhance quality in life (24), also for people living with diabetes and severe mental illness (25). Despite the call for collaboration between physical and mental healthcare sectors, many chronic care management interventions continue to focus on a single condition, even though service users self-management decreases as the number of conditions increases (26). Treatment of diabetes and mental illness is often treated separately; however, a combined view on both conditions does not only have positive effects on the target populations self-management but also on health economic (2,27). A recent non-randomized control study has highlighted that the integration of a mental health, social care, and diabetes model (Three Dimensions For Diabetes- 3DFD) have possible effects on biomedical and health economic outcomes (27).

Reviews focusing on combined interventions have studied people with severe mental illness and Type 2 diabetes, which has improved diabetes care (25) and pharmacological management (28), at the same time heightening awareness of the effects of self-management interventions (29). However, none of the interventions have a focus on involving users' own treatment choice in care planning. Nevertheless, considering the potential of interventions involving users' own treatment choice, we found it pertinent to investigate the extent and successfulness of its application on people with co-existing type 1 and 2 diabetes and severe mental illness. On the basis of this, we therefore decided to perform a scoping literature review, as scoping reviews are ideal to assess the nature and extend of current research (30,31). The aim of this scoping review was to describe the existing empirical literature on interventions to optimize the treatment of people diagnosed with co-existing diabetes and severe mental illness involving the users' own treatment choice.

Methods

A scoping review was conducted in accordance with the guidelines of the PRISMA Statement for Scoping Reviews (31). Scoping reviews are of value in identifying gaps in the current research and offer a course for future research (30), while they are also conducted to summarize and synthesize evidence for the information of several levels of society (practitioners, policy-makers, etc.). Scoping reviews are used in order to scope a large field of studies and have same requirements of transparency of reporting and rigorous methodology as the systematic review (32).

Eligibility criteria

Studies describing diabetes as *Type 1* and/or *Type 2 diabetes*, or *diabetes* were included. Studies published in the English, Danish, Swedish, or Norwegian languages were included. Only publications since 2000 to July 2020 were of interest. This was a pragmatic cut off as contextual differences in medications and other clinical practice could influenced ability for comparison.

Information sources

Assisted by a research librarian, the first author (VZ) performed the literature search on 22 July 2020, using the MEDLINE, Embase, PsycINFO, Web of Science, Cinahl, and the Cochrane Library databases. SveMed+ was searched using a simple search string to also identify publications in Scandinavian languages. Inspired by the CADTH Grey Matters checklist, a search for gray literature was performed in the OpenGrey (System for Information on Grey Literature in Europe), Google Scholar, and Danish Health and Medicine Authority databases (33).

Search strategy

The search terms covered three overall categories: severe mental illness, diabetes, and treatment choice. An example of a full search strategy from Embase is provided as an appendix (figure 2). To accommodate differences in medical subject headings MeSH, the search strings were adjusted specifically to each database.

Selection of Sources of Evidence

Preparation of the review began by making a chart by outlining criteria for eligibility. Three reviewers (VZ, SR and DH) independently screened the titles and abstracts of each source to exclude studies that did not meet the eligibility criteria. Afterwards, the reviewers independently screened the full text of the included articles. Retrieved papers were read in full and references followed up for final inclusion of studies. Disagreements on inclusion were resolved in eight cases by involving a fourth author (SA).

Types of studies

We included studies, which described interventions for people living with severe mental illness and type 1 or 2 diabetes. The studies had to incorporate the users' own treatment choice. Included studies could be RCT studies, intervention studies, cohort studies and case based studies.

Types of participants

Adults living with coexisting diabetes and severe mental illness. Adult participants were defined as those of 18 and older. Participants had to be diagnosed with type 1 or type 2 diabetes. We defined severe mental illness as schizophrenia, bipolar, major depressive disorder, non-organic psychotic disorder, including schizoaffective disorder, and personality disorder. The definition of major depression could be based on self-reported symptoms or on psychiatric assessment.

Types of interventions

We included studies, which described interventions with an incorporation of the users' own treatment choice in care planning. The interventions had to be comparable to our classification of *involvement of treatment* choice (view table 1).

Data charting process

To provide an overview of the included studies, key information was extracted by the first author (VZ).

Notes were taken for a data chart stating author, year, study aim, intervention design, settings, study population, and follow-up. The chart (Table 2) facilitated the description of the content and format of the interventions described in the included studies.

Data items

Types of outcomes

Primary outcomes

- Descriptions of the participants' involvement and treatment choice during the intervention
- User experiences
- Challenges on providing the intervention

Secondary outcomes

- Diabetes outcomes
- Mental health outcomes

- Other outcomes

Results

Selection of Sources of Evidence

The literature search retrieved 5166 articles from MEDLINE (635), Embase (2827), PsycInfo (673), Web of Science (240), Cinahl (556), the Cochrane Library (232), SveMed+ (3). Additional records were identified through OpenGrey (10). The removal of duplicates reduced the number of records to 4320. The selection process is summarized in a PRISMA flow diagram (Figure 1). The search results were managed in EndNote version X8; to support the reliability of the study selection, the search results were afterward screened in Covidence© to manage the search process.

Characteristics of Sources of Evidence

The included studies consisted of: five randomized controlled trials (34–40), a single case description of combined treatment (41), one retrospective cohort study (41), one naturalistic intervention program (42), one case vignette (43), and last a tailored diabetes education intervention program (44,45). Besides one study from Canada (45), all were conducted in the U.S. Primary outcomes will be described in this section; however, the studies used different measurement tools. Table 3 provides further details on the used tools. Participants of the included nine studies fell into two major categories; users of mental health service and users who were not treated in the mental health service. Five studies were focused on diabetes care in a target population consisting of patients with different mental disorders such as schizoaffective disorder, bipolar disorder, or major depression (34,41–44) receiving treatment in a mental health care setting. The other four studies were focused on interventions for and outcomes of major depression or/and dysthymia and the target population included people with co-morbid diabetes and depression disorder. In the latter studies, major depression was diagnosed by screening with self-report instruments, when visiting primary care clinics. Patients receiving lithium or anti-psychotic medication and/or received treatment in mental health care was excluded (35–40,46). The main duration of treatment ranged from 9 to 40 weeks.

The nine programs operated with different healthcare team collaborations, with the participation of several healthcare professions. For four of the included studies, the use of nurses as care managers was a shared trait (34,35,41,42). In the 2017 Chwastiak et al. study, care management was shared with a registered dietitian (41). The care manager's tasks included the coordination of care with medical

specialists to structure a comprehensive health assessment resulting in individual healthcare plans and education for service users in illness management (34,41,42). Besides nurses and a dietitian, several of the programs included other health professionals, such as a psychiatrist, a medical consultant (endocrinologist), a clinical pharmacist, primary care physicians, and medical assistants (34–37,41,43,46).

In six of the programs, staff was trained in the delivery of the intervention (34–36,41,42,46). The training encompassed among other program monitoring, delivering, psychopathology, pharmacotherapy, and problem-solving treatment (34–42,46). In seven of the nine programs, there was a focus on health and psychoeducation (34,35,37,41–43,45). In two of them, a care manager provided a 30-minute visit to train illness self-management through improved nutrition, medication, and physical activity (34,41). This took place every week for the first twelve weeks, then every month for up to six months (34). In the study by William et al. 2004, the intervention group received a 20-minute educational videotape plus a booklet on late-life depression (35). The tailored diabetes education program focused on four teaching topics: Understanding diabetes, nutrition, exercise, and behavioral.

Results of individual sources of evidence

For each individual study, relevant data relatable to the review question and objectives are presented in details in table 2.

Synthesis of results

Participants' involvement and treatment choice during the intervention

User preferences and concerns were reported in all studies and were related to the service users' treatment or self-management of their diabetes (43,45), their mental illness (35–40,46) or both (34,41,42).

In the majority of the interventions, the users' preferences were elicited to develop individual healthcare plans (34,37,41–43). The approaches varied; in some of the studies, the individual healthcare plans integrated the user's knowledge to support a healthy lifestyle (43) and involved family members, friends, and neighbors (37,42). In two studies, individual healthcare plans were prepared at the beginning of the intervention, integrating user preferences based on motivational interviews with service users performed by a health professional, such as the care manager. The interviews targeted health behavioral change and addressed barriers to effective self-management (34,41) and behavioral activation to target negative symptoms of schizophrenia, depression, and to decrease or end the use of tobacco, alcohol, and illegal

substances (34). Three studies presented different treatment options from which the service user could choose (35,36,46). By participant learning, the tailored education program varied the teaching sessions based on the participants' learning style. This to change teaching strategies and the need for support (45). For example, a further individualization of the education was achieved by discussing the user's diabetes-related health goals (e.g. in relation to nutrition and concerns on heart diseases) and implementing the goal in the sessions (45).

In all studies, the healthcare plans and treatment options were changed during the intervention period in collaboration with the service user. This happened if expected changes in health outcomes (mental illness or diabetes symptoms) failed to occur (34–37,41,42,46), changes in the service user's preferences (43), or cultural adaptations (37). Furthermore, in some studies the duration of the intervention period was adapted to suit the individual service user's need for support (34,42). In one study, the user and the clinical pharmacist discussed dietary preferences. The service user expressed concerns about injecting himself. Based on the concerns the pharmacist and the user decided that the injections were given by the clinical staff once a week in the clinic (45).

. Based on the service users' preferences and needs, one study incorporated open discussions on diet issues, medication and exercise as a part of the consultations (43). The last study focused on depression education targeting user and family members (37,40).

User experiences

To measure the users' satisfaction with the programs, seven of the studies elicited their response to the intervention and their satisfaction in terms of meeting their personal treatment preferences (34,36,40,42,43,45,46). Three studies used a self-reported satisfaction questionnaire for the service users (36,42,46). Four studies performed interviews with the participants or used users' anecdotal stories (34,40,43,45).

Two studies described general satisfaction among users receiving the intervention, using global satisfaction scores (36,46). Another study reported high user satisfaction because of the successful inclusion of the users' preferences and the possibility of returning to the program after dropout (34). Some service users also reported their satisfaction with achieving a deeper understanding of nutrition and diabetes (42,45) and the satisfaction with the combined view on both diseases (45). Some of the interviews revealed that the program's combined focus on both conditions and the healthcare

professionals' better understanding of the participants' situation had made healthcare more accessible (34). The same service users also reported that they saw the limited duration of the intervention period as a crucial weakness of the collaborative care model. The service users highlighted, to achieve and sustain clinical improvement, a longer period than the planned six-month intervention was necessary (34). In one study the service users reported satisfaction with their emotional care (40) and one user describes positive changes in mental health symptoms (43). Although most of the included studies reported patient expectations and satisfaction with the interventions, only one described of service user- provider barriers during the treatment planning. Most descriptions reflected the service user's poor mental health status at the beginning of the intervention, and how this affected the intervention (43).

Challenges of providing the intervention

In discussing the issue of providing care for people with coexisting severe mental illness and diabetes, three studies reported three major issues when integrating care for this target group.

First, communicating and coordinating care with general healthcare providers was one of the reported challenges. Such challenges increased with the geographic or administrative distance from the mental healthcare center (34,41,42). One study reported that general healthcare providers would typically focus on a single illness condition, suggesting that a combined focus on diabetes and mental healthcare would require more time from the providers (42). This was exemplified by nurses receiving medical lists from primary healthcare providers in which the psychiatric medication was often missing (42).

Second, one study reported, that the intervention group experienced at least one change of healthcare provider during the program during the 16 visits (42). The study highlighted a collaboration with peers as a possible solution to this problem, in order to increase the sustainability of the intervention and to offer service users the possibility of meeting people in the same situation (42). Same study argues that future research on interventions should clarify the interaction of co-existing mental and physical illnesses on health and self-management activities and seek to identify predictors of successful self-management strategies across the two conditions as well as healthcare settings and providers (42).

Third, the tailored diabetes education program reported challenges in developing the program for people with mental illness and diabetes. They reported that people with mental illness conditions are more likely to experience homelessness or have limited access to food. Hence, the diabetes program recommendation on diabetes diet was not in accordance with community meal programs. Furthermore, some users could not afford the recommended dietary changes (45).

Discussion

Summary of evidence

This review has highlighted the scarcity of literature on interventions involving service users' own treatment choice for the optimization of the treatment of people diagnosed with severe mental illness and diabetes (Type 1 or 2). Nine different interventions have been studied here, with a focus on topics such as user education, support of illness management, training of the health professionals, and challenges in delivering the intervention, and illness outcomes were measured in all studies (34–37,41–43,45,46); seven of them also reported the users' experiences (34,36,40,42,43,45,46).

4320 articles were screened, of these several studies, focus on user-involving interventions for people diagnosed with a diabetes condition. In these cases, severe mental illness was often an exclusion criterion. This may indicate that intervention studies continue to be divided into two groups, one for diabetes and another for mental health. Furthermore, three of the nine studies focused primarily on diabetes treatment and outcomes (41,42,45), whereas the four depression interventions did not implement diabetes awareness as an equal part of their intervention (35,36,40,46). This could indicate a gap in the research literature and explain the scarcity of studies in this review, or the relative novelty of this research field. As stated in the introduction, there are various approaches and recommendations for the involvement of service users' own treatment choice in care planning. Despite such recommendations, suggestions for the physicians' engagement with personal healthcare plans in decision-making and clinical practice are scarce (15). This raises the question of when a user can be said to be "fully involved" and suggests a weakness of the interventions due to the limited flexibility to adapt to the individual's everyday life. While we are aware that our definition of *involvement of treatment choice* may lack in clarity, a narrower definition may have excluded relevant studies. As discussed, determining full involvement in own treatment is a complex matter. The broadness of our definition reflects the absence of precise guidelines for the healthcare professionals' engagement of the service user and personal healthcare plan in the decision-making process.

Even though, two of the five RCT studies showed a trend towards decline of HbA1c during the intervention (34,37), the RCTs with a 12 month of follow-up, reported that the HbA1c was unaffected by the intervention (35,36,40,46). It is unknown whether the intervention itself influenced the service user's diabetes self-management or the possible improvement was caused by the close contact with the healthcare providers. Qualitative research on service users' descriptions of separate psychiatric and

diabetes care, could be useful to provide an understanding of the challenges of being a service user in two settings and their wishes for future combined interventions.

The definitions of SMI were comparable across the three studies, except for major depression, which was defined as major depression with psychosis in one of the (34), whereas other studies included major depression and/or dysthymia as one data set (35,36). Also, depression was in some studies assessed through self-reported instruments (35–40,46), and in other cases diagnosed through psychiatric assessment (34,41–44). Besides the definition of major depression, the similar definition of SMI in the included studies strengthens the scope for comparison across the studies. Nevertheless, there were no data on differences in interventions based on the individual person's type of mental illness. In addition, Chwastiak et al. 2017 referred to the heterogeneity of the mental illnesses as the cause of difficulties in collecting the same treatment-to-target for psychiatric symptoms (41).

One of the nine studies did not provide a description on which diabetes conditions the included participants had (35). Four studies involved both people diagnosed with Type 1 and Type 2 diabetes (36,37,42,46), whereas the last three studies included only people diagnosed with Type 2 diabetes (34,41,43), and one study included Type 2 diabetes and prediabetes (45). However, the studies that included both type 1 and type 2 diabetes do not differ between health outcomes in the participants diagnosed with type 1 or 2 diabetes (36,40,42,46). Differences in the studies' inclusion appeared, as two of the studies had specific criteria for the hb1Ac- level (41,43). This might affect the possibility of comparing not only the health outcomes of the interventions but also differences in the interventions, for example concerning the presence or absence of individual healthcare plans. Previous work has highlighted differences in daily living and coping among people with Type 1 and Type 2 diabetes (47,48) and how this can affect the applicability of comparisons.

Limitations

Several limitations require further considerations. The review only included articles published in English, Danish, Swedish, or Norwegian languages. Moreover, the review did not include literature published before 2000. It is possible that intervention studies applicable for this review, are excluded due to the narrow search limitation based on language and year of publication. Hence, these limitations could influence the possibility to provide a complete overview of current literature (31). Besides one study (45),

all included studies were conducted in the U.S., the findings may not be relevant or transferable to healthcare settings in other countries, requiring further research on this area.

Conclusion

This review included nine studies undertaken in U.S and Canada. The studies examine different ways to optimize the treatment of people diagnosed with diabetes and severe mental illness, all involving the users' own treatment choice in care planning. They share the aim of testing the effect of a multidisciplinary health team effort and the exploration of the feasibility of implementing interventions for people diagnosed with diabetes and severe mental illness. Our review has emphasized the difficulties of combining healthcare for people with severe mental illness and diabetes. The reviewed studies have reported unequal attention to both illnesses during the intervention process, difficulties of the communication and coordination of care efforts with other healthcare providers, and the questions of when and how users can be said to be involved in their care. We also highlight the potential of combining care, as this appears to have a positive effect on such outcomes as self-management, user experiences, and health effects. However, based on the limited evidence, the ability to draw conclusions is constrained and more research on this area is needed. User-involving interventions available for people diagnosed with co-existing diabetes and severe mental illness could be a solution to provide an equal awareness on both diseases and outcome, flexible healthcare plan re-adjustable to user preferences, and regulation of healthcare settings in order to improve collaboration between practitioners.

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Table 3. Tools for measurement

		Chwastiak 2017	Chwastiak 2018	Chiverton 2007	Hamm et al. 2017	Cimo et al. 2020	Ell et al. 2009-11	Ciechanowski et al. 2006	William et al. 2004	Katon et al. 2004
PHYSICAL HEALTH						X				
Hb_{A1c}	Average blood glucose for the last two to three months	X	X	X	X	X	X	X	X	X
Body Mass Index (BMI)	An index to linking height to weight	X	X				X			
Low- density lipoprotein (LDL)	Cholesterol level	X	X							
systolic blood pressure		X	X							
The Summary of Diabetes Self-Care Activities Questionnaire	A self-report questionnaire of diabetes self-management						X		X	
MENTAL HEALTH										
Patient Health Questionnaire-9 (PHQ-9)	self-reported depression measurement scale	X	X				X			X
SCL-20 depression scale	Measure changes in depression						X			
SCL-90 depression scale	Measure changes in depression									X
HSCL-20 depression scale	Measurement of depression severity							X		
Brief Psychiatric Rating Scale (BPRS)	Measures psychiatric symptoms such as depression and hallucination		X							
Sheehan Disability Scale (SDS)	Functional impairment I school, work,					X	X			

	family and social life									
6- Item BSI anxiety module	To access symptoms of anxiety					X				
Hopkins Symptom Checklist 90	Short self-report psychometric questionnaire. To evaluate psychological problems and symptoms of psychopathology									X
Two standard questions from SCID	To access dysthymia					X				
Diagnostic and Statistical Manual of Mental Disorders fourth edition (DSM-IV)	Screen for major depression And/or dysthymia								X	
Primary Care Evaluation of Mental disorders Patient Health Questionnaire	Score for major depression								X	
PATIENT SATISFACTION										
Self-reported patient satisfaction questionnaire (CSQ-8)	Assessment of patient satisfaction					X				
Exit interviews with the patients	Interviews users' after end intervention		X	X	X		X			
6- item version of the Health Care Climate Questionnaire	Measurements of autonomy support in the health care setting							X		

5-point ordinal scale	Rating treatment from poor to excellent							X		
OTHER										
Fagerstrom Nicotine Dependence Scale (FNDS)	A tobacco intervention training program		X							
Health risk status: Gordian Personal Health Analysis^f	Addressing the clients' readiness to change and lifestyle factors					X				
Childhood Trauma Questionnaire (CTQ)	To identify different childhood trauma such as sexual abuse, violence, divorce etc.							X		
Social Evaluation List (ISEL)	Social support							X		
MOS Short-Form Health Survey (SF-12)	Self-reported measurement tool to assess the impact on health and quality of life						X			
4-items Relationship Questionnaire	To assess attachment styles. The items consisted of 7-level Likert Scale response							X		
CAGE Questionnaire	Evaluate current drinking problem								X	

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Table 1: Eligibility and exclusion criteria		
	Rationale/Clarification	Search terms MEDLINE
Severe mental illness:	This category included schizophrenia, bipolar, major depressive disorder, non-organic psychotic disorder, including schizoaffective disorder, and personality disorder. The definition of major depression could be based on self-reported symptoms or on psychiatric assessment. We did not include mild-moderate depression as this is considered a common condition treated by general practitioners. In contrast, major depression often requires specialist treatment (6).	mental disease/ exp depressive psychosis/ or exp major depression/ or exp treatment resistant depression/ exp schizophrenia spectrum disorder/ exp affective psychosis/ or exp major affective disorder/ or exp schizoaffective psychosis/ exp mania/ exp personality disorder/ ((mental or psychiatric) adj3 (disorder* or illness* or disease* or diagnosis or diagnoses)).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.
Diabetes:	Studies describing diabetes as diabetes mellitus, type 1 or type 2 diabetes were included. Other diabetes conditions, such as gestational diabetes, were excluded.	As the two types of diabetes are often conflated into simply <i>diabetes</i> , we used <i>diabetes mellitus</i> as a single string in order to avoid excluding relevant literature. exp diabetes mellitus/ diabet*.tw.

<p>Involvement of treatment choice:</p>	<p>Despite a broad support for involving service users' treatment choice in care planning, there is no clear consensus about how to define a service user being fully involved in health care decisions. As a consequence, involvement of service users might vary across different health care settings (25,26). To accommodate this, we included only studies who involved users in own treatment and/or close collaboration between the service user and health professionals. We defined involvement of service users as a description of: individualized treatment based on the service user's preferences and values e.g. different medical and/or non-medical treatment options, need for support, or/and an individualized healthcare plan. There had to be a description of how data for the personal healthcare plan was collected. As previously mentioned, physicians' engagement in personal healthcare plans in clinical practice and decision-making is scarce. Included studies had to provide a</p>	<p>exp shared decision making/ exp decision making/ exp doctor patient relation/ exp patient participation/ exp interpersonal communication/ exp health literacy/ exp patient self-determination act/ ((patient* or person* or consumer* or citizen* or user* or client* or people) adj3 (negotiat* or communicat* or dialog* or consensus or agree* or decision or decide* or involv* or conversation or engage* or collaborat* or engag* or interact* or participat* or inclu* or choice* or centered)).tw. (SDM or decision making).tw. (collaborative adj3 (care or behavior*r*)).tw.</p>
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	<p>description of how the user preferences were integrated and how this affected the intervention. For example, if users' preferences affected the length of the intervention. This could be based on users' need for support or a shift in medication.</p>	
<p>Service user:</p>	<p>We have chosen to use the term "service user" or "user" throughout this article. However, we added "patient" in our search, as literature on shared decision making tend to use this term (24), to emphasize that the term "patient" can be preferred by the service users in some contexts (25), and to underscore the challenges in changing communication skills among health professionals (26). Hence, challenges in changing communication skills could be reflected in current research as well.</p>	<p>To ensure an all-encompassing view of the term <i>user</i>, our initial search strategy was to use combinations of the words <i>patient</i>, <i>person</i>, <i>consumer</i>, <i>citizen</i>, <i>user</i>, <i>client</i>, and <i>people</i>.</p>
<p>Studies were excluded if they were systematic reviews or META analyses</p>	<p>As these studies used different eligibility criteria, compared to our review. The reference lists of relevant reviews and META analyses</p>	

Book chapters, protocols, conference abstracts, and clinical guidelines	were inspected to identify original studies, and included these if they meet our eligibility criteria References in book chapters, protocols, conference abstracts and clinical guidelines were included if they meet our eligibility criteria. Included studies are recorded under “additional records identified” in the PRISMA flow chart	
<p>We did not exclude studies based on quality assessment as this is not characteristic for a scoping review (28,29).</p> <p>We did not provide a critical appraisal of individual sources, as scoping reviews provides an overview of existing literature regardless of the methodical quality and potential risk of bias (29).</p>		

Table 2: Data charting

Study and country	Study aim	Setting and study design	Intervention/ number randomized	Frequency/ follow- up time	Inclusion criteria For mental illness and diabetes diagnoses	Exclusion criteria For mental illness and diabetes diagnoses	Diabetes diagnoses SMI diagnoses	Diabetes outcomes interventio n gr.	Mental health outcomes intervention gr.	Other outcomes intervention gr.
Chwastiak et al. 2017 USA	Demonstrate the feasibility of a collaborative care program in primary care clinic.	Urban safety-net internal medicine clinic United States Retrospective cohort study	Multi-condition collaborative care All participants (n=634) Intervention group (n=151) People with SMI (n=52) Usual care (n=483) People with SMI (n=99)	Mean duration time of treatment 39.8 weeks. Mean number of visits 5,3 March 1, 2013- November 30, 2014	People diagnosed with severe mental illness (no definition), substance use disorder, and psychotic disorder. Receiving second generation of antipsychotic medication. Type 2 diabetes (HbA1C > 9%).		Type 2 diabetes Major depression Intervention group (n=33) Usual care (n=60) Bipolar disorder Intervention group (n=13) Usual care (n=19) Schizophrenia or other psychotic disorder Intervention group (n=6) Usual care (n=20)	Decline of HbA1c levels during intervention	No descriptions	
Chwastiak et al. 2018 USA	To evaluate and compare a collaborative care model aimed to treat people with diabetes and mental illness with standard care.	Two community mental health centers A multisite randomized controlled pilot study	Collaborative care All participants (n=35) Intervention group (n=18) Usual care (n=17)	Mean duration of treatment 14.8 weeks (range= 9-27 weeks) 3 month follow-up April 2013- September 2015.	Users were primary diagnosed with schizophrenia, schizoaffective disorder, bipolar disorder, or major depression with psychosis. Type 2	Cognitive impairment, that required informed consent, disability requiring psychiatric hospitalization, current suicidality and homicidally	Type 2 diabetes schizophrenia, schizoaffective disorder (more than 40% of the users in both groups), bipolar disorder and major depressive disorder with psychosis	Decline of HbA1c levels during intervention	No changes were found in psychiatric symptoms	

					(HbA1c > 8%) diabetes establish at least six months before enrollment				
Chiverton 2007 USA	To describe the effect of a multidisciplinary health team intervention program: The well Balance Program	Community care A novel clinical program	8 step program to integrate nursing and mental healthcare coordination services Clients (n=87)	Participants completed the 16-week program (n=74)	Severe mental illness (no definition), Type 2 diabetes.		Type 1 diabetes (15%) Type 2 diabetes (85%) Schizophrenic disorder (46%) Personality disorder (23%) Substance abuse (66%) Mood disorder (49%)	Decline of HbA1c levels during interventio n	No descriptions t in health risk status, and diabetes knowledge.
Hamm et al. USA	To explore a novel approach to diabetes care embedded within a community mental health setting by applying principles of person-centered diabetes care to those with SMI	A case vignette in a primary care setting	All participants n=(1)	11 months	Chronic severe mental illness and poorly controlled diabetes		Type 2 diabetes Schizophrenia	Decline of HbA1c levels during interventio n	Positive improvement of user experienced mental health status
Cimo et al. 2020 Canada	To investigate if a tailored diabetes education intervention affected diabetes	A community mental health organization. A tailored education intervention program	n= (7) six service users consented to have their outcome	The education consisted 12 sessions and was delivered between	Severe mental illness defined as: schizophrenia, schizoaffective disorders, bipolar	Experienced pregnancy, not responsible for managing their own diabetes, were	Type 2 diabetes (71%) Prediabetes (29%) Schizophrenia (n=4) Schizoaffective disorder	Fluctuating HbA1c levels during the interventio	No descriptions

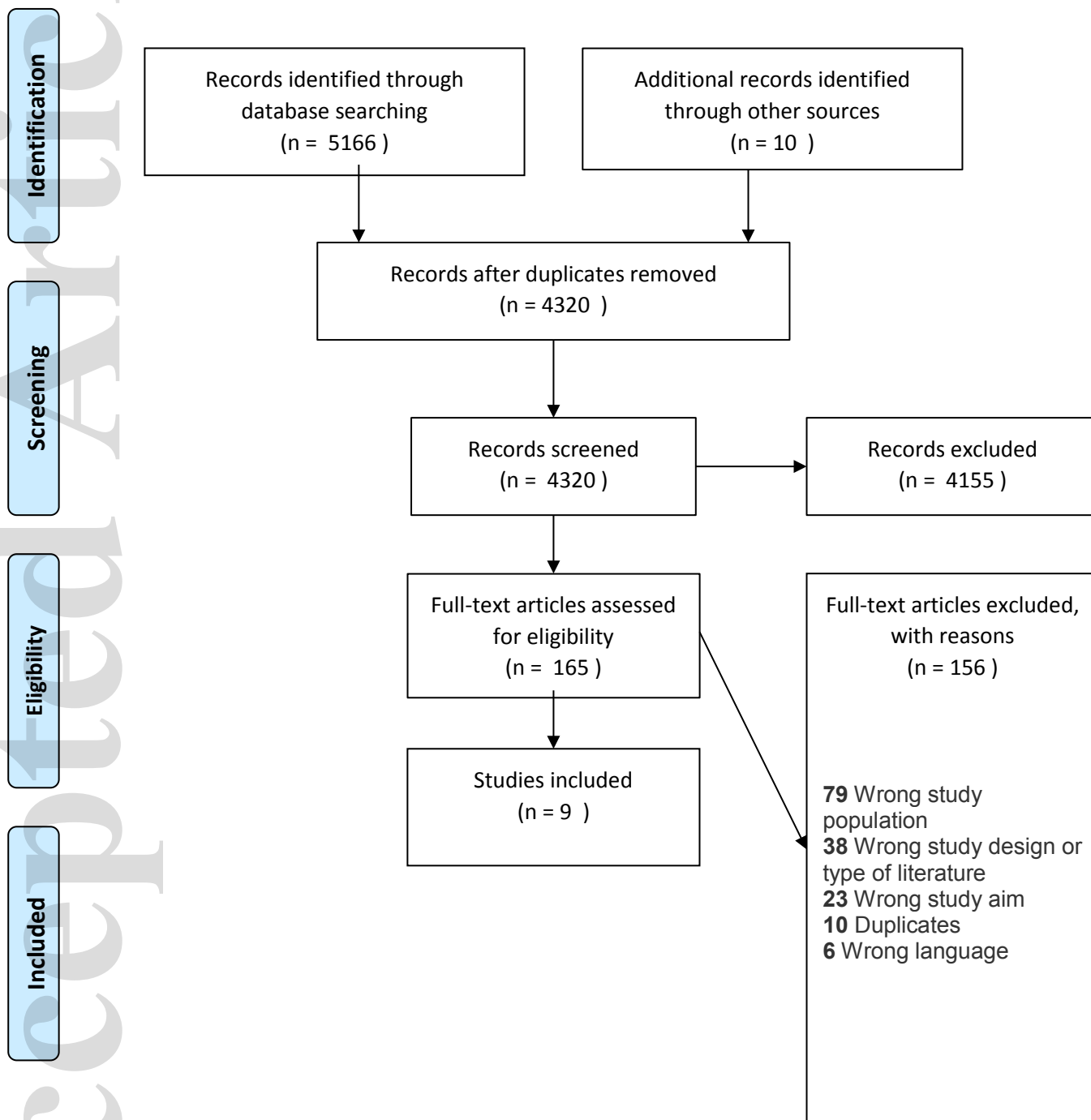
	insight of mental health-care users		measure data to be used	November 2017 and December 2018	disorders, or major depressive disorders	diagnosed with learning disability or deaf/blind impairment that would require extra tailored intervention, or medication changes that could impact their weight and blood sugar levels	(n=1) Mood disorder (n=1)	n		
Ell et al. USA	Tested if sociocultural adapted collaborative care program might reduce depression symptoms and increase user adherence to diabetes self-care regimes, glycemic control, and quality of life.	2 public safety-net clinics Randomized controlled study	Collaborative care All participants (n= 387) Enhanced care (n=194) Intervention (n=193)	Mean duration of psychotherapy 6-12 weeks 6,12,18 and 24 follow-up August 2005- August 2007	Major depression and diabetes	Current suicidal ideation, alcohol abuse or self-reported recent lithium/antipsychotic medication use	Type 1 (2 %) Type 2 (98 %) Major depression (100 %)	Decline of HbA1c during the intervention, but unaffected after 12 month follow up	Improved depression outcome compared to enhanced care	More psychotherapy or antidepressant use
Ciechanowski et al. USA	To determine if relationship style in people diagnosed with diabetes receiving depression	9 health maintenance organization clinics Randomized controlled study	Collaborative care All participants (n=324) Intervention (n=160)	3,6 and 12 month follow-up	Major depression or/and dysthymic disorder Diabetes	Bipolar or schizophrenia disorders, receiving psychiatric care, receiving antipsychotic or	Type 2 diabetes (n= 301) Type 1 diabetes (n=13) Major depression (n=212) Lifetime dysthymia (n=225)	HbA1c levels unaffected by the intervention	Improved depression outcome compared to usual care	

	treatment was associated with differential quality of care and depression outcomes.		Usual care (n=164)			mood stabilizer medications, or significant cognitive impairment					
Willian et al. 2004 USA	To investigate if collaborative care intervention would improve affective symptoms, functional status, self-care behaviors and glycemic control.	18 primary clinics Randomized controlled study	Collaborative care Overall sample (n=1801) Intervention (n= 212) Usual care (n=205)	Mean duration of treatment 12 months 3,6 and 12 month follow-up July 1999- August 2001	Major depression or/and dysthymic disorder.	Current drinking problem. History of psychosis, bipolar disorder, ongoing psychiatric care, or cognitive impairment	Diabetes (n=232) Major depression Intervention (n=24) Usual care (n=27) Major depression and dysthymia Intervention (n=122) Usual care (n=124)	HbA1c levels unaffected by the intervention	Improved depression outcome compared to usual care	Of the self-care behavior: Foot inspection, weekly exercise, diet, prescribed medication, glucose testing: Improvement appeared only in exercise behavior	
Wayne et al. 2004 USA	To examine if enhancing quality of depression care improves both depression and diabetes outcomes	9 primary care clinics Randomized controlled study	All participants (n= 329) Intervention (n=164) Usual care (n=165)	3,6 and 12 month follow-up Randomized trial with recruitment 1. Marts 2001-31. May 2002	Major depression or/and dysthymic disorder.	Currently in care with psychiatrist. Diagnosed with schizophrenia or bipolar disorder. Treatment with	Diabetes, not defined Intervention (n=7) Usual care (n= 7) Type 2 diabetes Intervention (n=157) Usual care (n=158)	HbA1c levels unaffected by the intervention	Improved depression outcome compared to usual care		

in people with both
diseases

antipsychotic mood
stabilizer. Mental
confusion or
dementia

Figure 1 PRISMA 2009 Flow Diagram



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Figure 2: example of search string Embase

Search strategy 02 07 2019. Updated 22 07 2020

Database: Embase <1996 to 2019 Week 26>

- 1 mental disease/
- 2 exp depressive psychosis/ or exp major depression/ or exp treatment resistant depression/
- 3 exp schizophrenia spectrum disorder/
- 4 exp affective psychosis/ or exp major affective disorder/ or exp schizoaffective psychosis/
- 5 exp mania/
- 6 exp personality disorder/
- 7 ((mental or psychiatric) adj3 (disorder* or illness* or disease* or diagnosis or diagnoses)).tw.
- 8 (schizo* or psychos?s or psychotic).tw.
- 9 ((bipolar or affective or personality) adj3 (disorder* or disease*)).tw.
- 10 ((major or unipolar or clinical or recurrent) adj3 depress*).tw.
- 11 (mania* or manic).tw.
- 12 SMI.tw.
- 13 or/1-12
- 14 exp shared decision making/
- 15 exp decision making/
- 16 exp doctor patient relation/
- 17 exp patient participation/
- 18 exp interpersonal communication/
- 19 exp health literacy/
- 20 exp patient self-determination act/
- 21 ((patient* or person* or consumer* or citizen* or user* or client* or people) adj3 (negotiat* or communicat* or dialog* or consensus or agree* or decision or decide* or involv* or conversation or engage* or collaborat* or engag* or interact* or participat* or inclu* or choice* or centered)).tw.
- 22 (SDM or decision making).tw.
- 23 (collaborative adj3 (care or behavio?r*)).tw.
- 24 or/14-23
- 25 exp diabetes mellitus/

26 diabet*.tw.

27 or/25-26

28 13 and 24 and 27