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Improving health outcomes for adults with severe mental illness and comorbid diabetes: is supporting diabetes self-management the right approach?

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Key words

Psychosis, severe mental illness, diabetes, self-management, structured education, multi-morbidity

Introduction

Diabetes is a common problem in people with severe mental illness (SMI is an umbrella term used to describe disorders in which psychosis occurs, and includes schizophrenia and bipolar disorder), and is associated with poor health outcomes and reduced life expectancy (Holt and Mitchell, 2015). Prevalence estimates pooled across 42 international studies suggest that around 13% of the SMI population has diabetes (Ward and Druss, 2015), a figure more than twice that in the general population (Shaw*, et al.*, 2010) . This inequality is likely to increase, as recent analyses of primary care data show diabetes prevalence increasing year-on-year for the whole population, with the *difference* between people with and without SMI widening (Reilly*, et al.*, 2015, Ward and Druss, 2015).

We have established a multidisciplinary research programme called DIAMONDS (**Dia**betes and **M**ental Illness: Improving **O**utcomes a**nd S**ervices), which aims to increase understanding about the comorbid relationship between diabetes and SMI, and develop effective interventions for people living with both these conditions. In this paper, we explore whether supporting diabetes self-management, which is the cornerstone of good diabetes management, offers the right approach. We draw on evidence from the diabetes and mental health literature to outline why improving

diabetes care for people with SMI is important; consider why diabetes self-management education offers the potential to improve health outcomes; discuss the risks of using this approach for people with SMI; set out the key research questions that need to be answered in order to make this approach work; and consider the implications for mental health nursing.

Why is it an important area?

People with SMI have poorer physical health and a reduced life expectancy by around 15-20 years when compared to the general population (Brown*, et al.*, 2010), with higher rates of modifiable cardiovascular risk factors (Osborn*, et al.*, 2015), and increased prevalence of a range of chronic health conditions including metabolic syndrome, diabetes, cardiovascular disease, stroke, and asthma (Reilly*, et al.*, 2015). The increased risk of developing diabetes and its associated complications, (which include cardiovascular disease, retinopathy, cerebrovascular disease, nephropathy and neuropathy), contributes significantly to the poor physical health and shorter life expectancy seen in people with SMI compared to the general population (Vinogradova*, et al.*, 2010).

Reasons for the comorbid relationship between diabetes and SMI are related to a combination of factors, which are likely to be synergistic and interactional in ways that we are yet to understand (Ward and Druss, 2015). These include: genetic features and symptomology associated with the mental illness; metabolic side effects of psychotropic medications; lifestyle factors, such as higher rates of smoking and alcohol intake, physical inactivity and poor diet; presence of other physical co-morbidities; and wider socio-economic inequalities (Holt and Mitchell, 2015, Ward and Druss, 2015). The organisation of health services also plays a part, meaning that, for people with SMI, their physical health needs are often neglected (Crawford*, et al.*, 2014). Explanations for

this include poor assessment, monitoring and recording practices; diagnostic

overshadowing, whereby physical health problems are attributed to the underlying

mental illness; ineffective co-ordination between primary and secondary care; and

ambiguity about who should manage the physical health needs of this patient group

(Lawrence and Kisely, 2010, Blythe and White, 2012, Crawford, *et al.*, 2014).

As with other multi-morbid populations, individuals with co-existing diabetes and SMI

are reported to receive fragmented and ineffective care (Scott, *et al.*, 2012). Diabetes

services for the general population vary considerably, and an international survey of

people living with diabetes, their carers, and healthcare staff, identified a need to

improve the provision of and access to appropriate diabetes care across all 17 countries

taking part (Holt, *et al.*, 2013, Nicolucci, *et al.*, 2013). Diabetes care for people with

SMI is likely to be even more variable, as it will depend on who provides their mental

health care and the level of knowledge among these clinicians about how to support

diabetes management (Blythe and White, 2012, Reilly, *et al.*, 2012). Additionally,

healthcare professionals can sometimes make unfounded assumptions about why people

with SMI have poor physical health, attributing blame to poor lifestyle and life choices,

and therefore fail to address other pertinent issues (Happell, *et al.*, 2012).

Tackling diabetes is a global priority, the cost of which accounts for approximately 12%

of the world's total health expenditure (Zhang, *et al.*, 2010). A large proportion of this

relates to treatment of complications that could be prevented through improvements in

diabetes management (Hex, *et al.*, 2012). The psychosocial impact of having diabetes

adds to the disease burden, with an increased risk of depression and distress reported in

numerous studies across varying patient populations (Nicolucci, *et al.*, 2013, Snoek, *et

al.*, 2015). Costs of diabetes in the SMI population have not been estimated, but are

likely to be disproportionately high given its increased prevalence and complications,

and underlying psychological vulnerability and associated burden of care (Bajor, *et al.*, 2015).

The World Health Organisation is committed to improving the physical health of people with SMI (World Health Organisation, 2013), and there is growing interest in developing lifestyle interventions to help achieve this (McGinty, *et al.*, 2015), mirroring developments in the general population through the national diabetes prevention programmes (Ali, *et al.*, 2012). Focusing on diabetes management is equally as important because achieving even modest improvements in key biological markers of diabetic control, including HbA1c, blood pressure and cholesterol, reduces the risk of complications and mortality, and associated healthcare costs (Kontopantelis, *et al.*, 2015). However, there is little evidence to suggest that this broader approach helps to improve diabetes management in addition to promoting lifestyle changes (Schellenberg, *et al.*, 2013). Additionally, there are few targeted diabetes interventions for people with SMI, and little understanding about how to effectively support this vulnerable patient group (Chwastiak, *et al.*, 2015).

Why focus on diabetes self-management education (DSME)?

Self-management aims to provide people with "the knowledge, skills and confidence to manage their condition effectively in the context of their everyday life" (Coulter, *et al.*, 2013). In diabetes, self-management has been a core component of clinical management since the 1950's, aimed at improving glycaemic control through lifestyle changes, self-monitoring of symptoms, and medication. Diabetes self-management refers to the skills, practices and behaviours that a person with diabetes engages in to protect and promote their health. These include: improving diet; increasing physical activity; smoking cessation; monitoring glycaemic control, blood pressure and lipids; preventing complications; and improving treatment adherence (Ahola and Groop, 2013).

A growing number of systematic reviews provide evidence that, for diabetes and other

long-term conditions such as chronic obstructive pulmonary disease and hypertension,

(which are also more prevalent in the SMI population (Reilly, *et al.*, 2015)),

interventions targeting self-management have clinically significant effects on a range of

important health outcomes (Taylor, *et al.*, 2014). In diabetes specifically, recent

systematic reviews of DSME programmes provide evidence that patients receiving

these interventions show significantly improved self-management, and more

importantly, diabetic control (as measured by HbA1c) when compared to patients

receiving routine care (Fan and Sidani, 2009, Steinsbekk, *et al.*, 2012, Chrvala, *et al.*,

2015).

DSME is already supported by international policy (International Diabetes Federation,

2012). Additionally in the UK, general practitioners are offered financial incentives (as

part of the Quality and Outcomes Framework) to refer patients for DSME, and there are

a number of established DSME programmes rolled out in practice, delivered by trained

dieticians, nurses and other healthcare staff (National Diabetes Audit, 2014). Adapting

an intervention that is already acceptable and feasible is more likely to be adopted by

healthcare staff and their patients (Greenhalgh, *et al.*, 2004). Being able to draw on

existing packages, resources and staff with the skills to deliver these also offers a

distinct advantage over developing new interventions, the feasibility of which is

unknown and may inadvertently increase rather than decrease existing health

inequalities.

Adopting a behavioural approach such as DSME may also be more acceptable than

offering adjunctive pharmacological therapies to alleviate the metabolic side effects of

anti-psychotic medications. It may also be preferable to the alternative of switching

from an anti-psychotic that has proven effectiveness in preventing relapse in SMI for an

individual, to one which has uncertain efficacy, but a more favourable metabolic profile (Chwastiak*, et al.*, 2015). Multiple drug therapy is increasingly used for managing SMI and is associated with poorer health outcomes (Correll*, et al.*, 2015). Compared to people with diabetes alone, people with SMI and comorbid diabetes are more likely to be prescribed multiple medications, which may change over time and interact in ways that require careful monitoring (Ward and Druss, 2015). Although problems with medication adherence, (the extent to which patients take their medications as prescribed by their healthcare provider (Osterberg and Blaschke, 2005)), is reported across many patient groups and health conditions, evidence suggests that it is a particular problem for people with SMI (Kreyenbuhl*, et al.*, 2010). DSME programmes offer the potential to address barriers to medication adherence encountered in this population.

A further advantage of this approach is that people who successfully self-manage their diabetes are less likely to experience diabetes-related distress or depressive symptoms compared to those who do not, although the evidence to support this is somewhat contradictory (Snoek*, et al.*, 2015). This is particularly important for people with SMI, due to their underlying psychological and emotional vulnerability, and their increased risk of comorbid depression and other affective disorders (Buckley*, et al.*, 2009). Finally, focusing on improved self-management may have positive effects on SMI management. In chronic health, the self-management model "lays emphasis on following essential process elements: (a) building self-efficacy; (b) self-monitoring; (c) goal-setting and action-planning; (d) decision-making; (e) problem-solving; (f) self-tailoring; and (g) partnership between the views of patients and health professionals" (Du*, et al.*, 2011). These behavioural strategies are commonly used in effective behavioural therapies for treating SMI, which are known to be acceptable to patients and those who support them (Jauhar*, et al.*, 2014).

What are the risks of using this approach for people with SMI?

Although supporting diabetes self-management may offer advantages over pharmacological and other behavioural approaches, many people struggle to make the necessary lifestyle changes to prevent complications (Ahola and Groop, 2013, Nicolucci*, et al.*, 2013). People with SMI face additional barriers to managing their health and having the confidence to do so (Roberts and Bailey, 2011). For example, illnesses like schizophrenia and bipolar disorder are characterised by disturbed thoughts, perception, affect, and behaviour, resulting in loss of motivation, impaired self-efficacy and poorer self-care (Chen*, et al.*, 2014). SMI is also associated with wider inequalities across a range of domains, with individuals obtaining fewer qualifications, more likely to be out of work and experience poverty, and to lack social support and live alone (Department of Health, 2011).

These features impact on lifestyle choices, for example people with SMI are more likely to smoke and engage in risky behaviours such as drug taking and alcohol abuse, have poorer diet and higher levels of physical inactivity (McGinty*, et al.*, 2015). People with SMI may therefore need to make multiple lifestyle changes upon being diagnosed with diabetes, and it may be that a gradual approach focusing on one aspect at a time, e.g. diet, exercise or medication adherence, is more appropriate than an intervention modelled on existing DSME, which tends to address multiple lifestyle factors (Steinsbekk*, et al.*, 2012). DSME programmes also expect people to attend regular group sessions, and there is some evidence to suggest that group-based DSME is more effective than an individual approach (Hwee*, et al.*, 2014). Unfortunately, this can be especially problematic for people with SMI who despite having more frequent and sustained contact with health services (Reilly*, et al.*, 2012) report numerous barriers to

engaging in health interventions, for example not having support from others, or lacking

the financial resources or transport to attend regular sessions (Kaufman, *et al.*, 2012).

Barriers to access are an important concern. In the general population, many people

with diabetes are often not referred for DSME (Holt, *et al.*, 2013), and anecdotal

evidence suggests that people with SMI are less likely to be referred or to attend DSME

programmes unless they are appropriately adapted. For example, ambiguity about who

is responsible for managing the physical health of people with SMI may mean that

individuals supported by specialist mental health services may not be in regular contact

with their general practitioner, who often acts as the gatekeeper to diabetes services.

Conversely, patients who are only supported in primary care, which are reported to be

around 20-30% of people with SMI, may not benefit from interventions situated within

mental health (Reilly, *et al.*, 2012).

A further risk of adopting this approach is that DSME programmes tend to be

predicated on normative assumptions about health literacy (defined as "the degree to

which people have the capacity to obtain, process, and understand basic health

information and services needed to make appropriate health decisions" (Parker, *et al.*,

2003)), and there is some evidence to suggest this is compromised in people with SMI

(Clausen, *et al.*, 2015). DSME interventions require participants to play an active role in

managing their health as well, and commonly employ techniques such as goal setting,

problem solving, and self-monitoring (Presseau, *et al.*, 2015). Although people with

SMI may be familiar with these strategies through management of their mental health,

they may well have lower self-efficacy and be less activated to make the necessary

lifestyle changes (Hibbard and Gilburt, 2014). People with SMI can also experience

multiple relapses of their mental illness, and may have chaotic lifestyles and cognitive

impairments which affect their ability to incorporate self-monitoring regimens into their

daily routines (Harvey and Strassnig, 2012).

Recent developments in DSME may be problematic for this patient group too. For

example, a growing number of programmes are using mobile phone and online

technologies to support lifestyle changes and medication adherence (Pal, *et al.*, 2014).

Although this approach has shown some promise in the SMI population, these patients

are less likely to own a smart phone than the general population and may have financial

constraints that compromise the feasibility of delivering an intervention that requires

users to regularly access the internet on their mobile phone (Naslund, *et al.*, 2015). How

to effectively utilise the increasing opportunities available through mobile health

technologies therefore requires careful consideration; however, at the same time not

using this technology may increase health inequalities if people with SMI are excluded

from an approach increasingly used to monitor and manage chronic health conditions.

Furthermore, while DSME interventions have shown some promising results, there is

considerable heterogeneity between individual studies, and few conclusions can be

drawn about the causal mechanisms and active ingredients that might be transferable to

specific populations (Fan and Sidani, 2009, Steinsbekk, *et al.*, 2012, Chrvala, *et al.*,

2015). For example, although the trial evaluation of DESMOND (a programme

commonly used in the UK) demonstrated greater weight loss and lower levels of

depression at 12 months, it in fact showed no significant improvements in diabetic

control (as measured by HbA1c) compared to usual care (Davies, *et al.*, 2008). In a

three-year follow up, there were no significant improvements in any of these outcomes,

which highlight uncertainties about the long-term effects of DSME, and the challenges

individuals face in sustaining lifestyle changes (Khunti, *et al.*, 2012). Additionally,

these interventions have not been tested in real world settings, where the positive effects

are sometimes not realised in practice (Ali, *et al.*, 2012).

How can we make sure this approach works?

We know that DSME programmes can be effective for improving diabetes outcomes,

but we do not know how to make this approach work for people who are diagnosed with

diabetes alongside SMI. There is a risk that unless current strategies to improve diabetes

self-management are adapted to take account of the particular characteristics and needs

of people with SMI, inequalities in morbidity and mortality experienced by this

population may widen as generic DSMEs are scaled up to meet international

recommendations for diabetes care.

We propose that a bespoke DSME programme for people with SMI has the potential to

improve diabetes outcomes and reduce modifiable cardiovascular risk factors. Such

programmes may also lead to better mental health through improved illness

management and lifestyle changes. However, there are some key research questions that

need to be answered in order to develop an evidence-based DSME intervention that is

acceptable to people with SMI and those who support them, and also effective in both a

trial and real world setting.

What are the determinants of self-management in people with SMI?

We already have a good understanding of the motivational, cognitive and psychological

deficits associated with SMI, and can speculate on how these might influence diabetes

management. Nevertheless, there are gaps in knowledge about the factors that inhibit or

alternatively enhance good diabetes management in people with comorbid SMI. These

include key characteristics about the population and their diabetes outcomes and care;

determinants of good and poor diabetes self-management; and the role of carers and others who support them, including, for example, mental health services.

Thanks to the increasing availability of large databases containing anonymised individual patient healthcare records, we have new opportunities to understand more about the factors that may influence diabetes onset and outcomes in people with SMI; including identifying which people with SMI are likely to receive poor diabetes care and are at greatest risk of poor diabetes outcomes (Herrett, *et al.*, 2015). We can also learn more about the potential mechanisms of action for improving self-management through configurative synthesis and modelling of multiple evidence sources (Gough, 2013). This approach to reviewing the literature and combining different evidence types can help to identify the most promising components and strategies to include in an intervention, as well as shed light on other important features that are likely to increase successful implementation and adoption.

Understanding the lived experience of diabetes alongside SMI is equally as important; and we are aware of only one qualitative study exploring diabetes experience in people with SMI (Blixen, *et al.*, 2016). Further research is required to explore barriers to accessing healthcare and support for diabetes; opportunities to exploit existing healthcare resources and new mobile health technologies to ensure feasibility of the programme; and consider whether a support or assets-based approach is needed due to the psychological and social vulnerabilities in this population. Including the views of health service staff, managers and commissioners will also allow for an exploration of the opportunities for delivering the intervention within secondary mental health, where staff already have the skills to effectively support people with SMI, and an appreciation of the motivational deficits and barriers inherent in this population.

What are the active ingredients for an effective DSME programme?

The combination of educational and behavioural elements distinguishes DSME, which aims to increase self-management behaviours, from traditional forms of didactic patient education, which tend to focus primarily on improving patient knowledge (Bodenheimer*, et al.*, 2002). Unfortunately, a significant proportion of published evidence in diabetes self-management fails to report interventions in sufficient detail, including not specifying which behaviour change techniques (BCTs), (defined as a "component of an intervention designed to alter or redirect causal processes that regulate behaviour; that is, a technique is proposed to be an "active ingredient" (e.g., feedback, self-monitoring, and reinforcement)" (Michie*, et al.*, 2013, p.82)), are used to effect change (Presseau*, et al.*, 2015). This lack of detail makes it difficult to select suitable existing interventions to adapt for populations who have particular comorbidities or motivational deficits requiring a more targeted approach.

With increased knowledge of the determinants of and resources for diabetes self-management in our target population, we can identify BCTs and other important components and delivery mechanisms that are likely to be most effective. This knowledge will also help us to consider how to utilise mobile health technologies to deliver tailored DSME, and to ensure that people with SMI do not miss out on the increasing opportunities to manage their health and illness remotely. For example, mobile phones may be used for goal setting, or providing feedback or practical support, which are commonly employed BCTs for diabetes management (Presseau*, et al.*, 2015). Modelling effective BCTs for diabetes self-management that correspond to key determinants of self-management behaviour in people with SMI offers a promising approach, already successfully employed for smoking cessation in this population (Gilbody*, et al.*, 2015). Using this approach also helps to ensure that any intervention

we develop can be replicated by others and implemented effectively (Craig*, et al.*, 2008).

What is acceptable and feasible for people with SMI?

Because of the limited evidence in this area, there is little known about what is acceptable for people with SMI and comorbid diabetes, and what is feasible to deliver and implement for a patient population receiving care from primary, mental health and diabetes care providers. To address issues of acceptability and feasibility, it is essential to work in partnership with service users, carers and healthcare professionals in addition to using qualitative enquiry to increase knowledge about what is needed. In the DIAMONDS programme mentioned above, we plan to use co-design methods to ensure that the bespoke intervention, including its goals, mode of delivery, structure and content, is acceptable to people with SMI and diabetes, and to maximise future take-up and engagement (Boyd*, et al.*, 2012).

Identifying and agreeing goals and outcomes is an essential step of intervention planning (Bartholomew*, et al.*, 2011) and can enhance implementation success by ensuring that the needs of different stakeholders are accounted for (Greenhalgh*, et al.*, 2004, Taylor*, et al.*, 2015). There is little consensus, however, about what to measure for people with multiple morbidities (Barnett*, et al.*, 2012), including comorbid diabetes and SMI. It will therefore be important to work in partnership with service users and carers, healthcare staff and others involved in managing and commissioning services to agree goals and outcomes to support future evaluation and implementation of interventions that are developed (Williamson*, et al.*, 2012).

Clinical adoption is also an important consideration (Greenhalgh*, et al.*, 2004), as mental health, primary care and diabetes clinicians are likely to be involved in

identifying a need for supporting diabetes self-management and referring patients for

appropriate interventions. Finally, while user and frontline staff acceptance is a key

driver of our work, we are also mindful to develop an intervention that can be

implemented into a changing healthcare landscape in which commissioning

arrangements and service priorities are continually evolving. Local commissioners will

therefore need to be involved to ensure that financial, technological and procurement

barriers, including intervention costs, are addressed as part of developing the

intervention (Taylor, *et al.*, 2015).

What are the implications for mental health nursing?

The interplay of biological, psychosocial, economic and healthcare factors that

contribute to poor diabetes outcomes in people with SMI highlights the need to develop

targeted support for people living with both conditions, to reduce unacceptable health

inequalities and improve life expectancy for these patients. Diabetes is increasingly

common in the SMI population, and mental health nurses and other staff involved in

supporting people with SMI therefore need to have appropriate skills and knowledge to

support patients living with comorbid diabetes. This could be achieved through

increased opportunities for training and professional development around management

of physical health conditions common in SMI, or by attending DSME programmes

alongside individual patients where skills and knowledge need improving.

Having diabetes can cause diabetes-related distress and depressive symptoms,

potentially impacting on SMI management and psychological wellbeing. Mental health

nurses and care co-ordinators, therefore, have an important role to play in addressing

individual patient barriers to accessing and attending DSME programmes and other

diabetes care interventions, and identifying the resources and additional support that

patients may need to make and sustain positive lifestyle changes, self-monitor their

diabetes symptoms, and adhere to new treatments. Better monitoring of the effects of new medications used to treat SMI alongside diabetes, due to the metabolic side effects of anti-psychotic medications and the unknown effects of combining multiple medications for more than one health condition, is also needed.

More broadly, there is a need to better monitor diabetes risk in the SMI population, not only to allow patients at high risk of diabetes to benefit from the growing number of diabetes prevention programmes being rolled out in the UK and other countries, but also to ensure that patients are diagnosed early and offered support to manage their diabetes. This will require an integrated and collaborative approach between primary, mental health and diabetes care providers, and mental health care co-ordinators have an important role in facilitating this. Finally, the metabolic effects of anti-psychotic medications are now well known, and associated weight gain can happen very rapidly for people prescribed these medications. Mental health nurses have an important educational role to ensure that patients are aware of this risk, and to help them manage the metabolic side effects alongside managing their mental illness.

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