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Introduction and background

A substantial body of literature has identified that people with learning disabilities (LD) have generally poorer health than the non-disabled population and are at greater risk of developing chronic illnesses (Brown, 2017; Emerson and Baines, 2010; Melville *et al*., 2008). This inequality exists due to complex, interrelated lifestyle factors in people with LD, including sedentary behaviour, poor diet and health literacy, dependency on caregiver support, access to primary care, and a lack of appropriately tailored educational resources.

Such a chronic disease is type 2 diabetes (T2D) which develops as a result of high levels of blood glucose (Diabetes UK, 2017). If left untreated, T2D leads to a reduced quality and duration of life (Balogh *et al*., 2015). High glucose levels can affect the heart and blood vessels, kidneys, eyes, and feet, potentially leading to infections, cardiovascular disease, strokes, blindness, amputation and death (Diabetes UK, 2017). Type 1 diabetes (T1D) prevents the pancreas from producing insulin. Without insulin, glucose builds up in the blood as it is unable to enter cells (Diabetes UK, 2017). As T1D does not occur as a result of lifestyle, its prevention is not possible and insulin must be externally administered, via injection or pump. However, as with T2D, it is important to minimize the build-up of cholesterol which can prevent glucose from entering cells. A balanced diet and adequate levels of exercise are therefore essential in order to prevent the development of further health complications. Symptoms of T1D may present from a young age, and during 2017 over one million children globally were reported as living with T1D (IDF, 2018).

Globally, diabetes is a growing problem and considered to be one of the largest health emergencies of the 21st century (IDF, 2018). In 2017 it was reported that approximately 425 million adults (20-79 years), worldwide, were living with diabetes, with an estimated projection of 629 million by 2045 (International Diabetes Federation (IDF), 2018). Within the UK some 4.6 million people have been diagnosed with diabetes (Diabetes UK, 2017), a prevalence of 6% in adults. Diabetes carries major cost implications to health services, a reported £23 billion in the UK during 2010/2011 (Diabetes UK, 2017), and 727 billion US dollars reported globally (IDF, 2018).

Recent research has focussed on how to address these issues and reduce the risk of developing diabetes, as well as improving self-management in those diagnosed with the disease. These approaches have identified the prevalence and incidence of diabetes in people with LD in the UK and globally. The support needs of people with LD, at risk of or living with diabetes, have been explored through qualitative work, including barriers and facilitators to lifestyle adjustment, together with the experiences of primary care workers and front line support staff. Mainstream approaches to diabetes prevention and management have been identified and evaluated in relation to the needs of people with LD. In tandem, intervention and prevention programmes have been adapted from mainstream programmes or newly developed, and have undergone feasibility trials with a view to engendering behavioural change. These trials have highlighted potential benefits but also demonstrated challenges in areas such as recruitment and retention of participants.

Each of these areas of research has implications for policy and practice, as well as for the development of future research. There is presently a need for a comprehensive update of developments in the research on diabetes and people with LD by assimilating the conclusions of recent studies, so that recommendations for policy, practice, research, and education, are emphasised with greater clarity and urgency.

Aims

The aims of this review are to provide a cohesive overview and update of literature which has been previously appraised systematically, covering the following areas: the demographics and prevalence of diabetes in people with LD; an overview of mainstream approaches to treatment; diabetes self-management and people with LD; and the coordination of services and supports for people with LD and diabetes. Implications for policy, practice, and research will be discussed in relation to these areas.

Methods

This review provides an update and integration of the findings from recent literature reviews on diabetes and people with LD (McVilly *et al*., 2014; MacCrae *et al*., 2015; Maine *et al*., 2018, 2019). Additional information beyond the review findings was sought directly from the studies cited in the reviews. The authors reached consensus on the themes to include through discussing and collating the overarching review findings.

Diabetes and people with learning disabilities

Two recent systematic reviews (MacRae *et al*., 2015; McVilly *et al*., 2014) reported that prevalence figures for T2D in people with LD were estimated to be 2-3 times higher than the general population. These disparities are prominent in women and younger adults, and in those living in rural or high-income settings (Balogh *et al*., 2015). People with LD are more susceptible to developing diabetes as they age due to many risk factors including family history and age (Haveman *et al*., 2011), gender (Sohler *et al*., 2009) ethnicity (Lanting *et al*., 2005), obesity (Melville *et al*., 2008), physical inactivity (Temple *et al*., 2006) medications such as anti-epileptics (Sankar, 2004), genetic conditions such as Down syndrome, Klinefelter syndrome, Prader-willi syndrome, Noonan syndrome and Williams syndrome (Anwar *et al*., 2004; De Winter *et al*., 2009) and cardiovascular disease (WHO, 2013). People with LD also have higher rates of hospital admissions from diabetes-related conditions that might otherwise be expected to be successfully managed on an outpatient basis (Glover *et al*., 2012).

Management of type 2 diabetes

Traditional management of T2D is based on medication, diet and lifestyle modifications, supported by the patient's GP, practice nurse and/or diabetes specialist nurse (DNS), with three monthly visits to the health centre (Department of Health (DoH), 2001). In diabetes care, self-management and education are considered core elements of reducing risk factors and long-term disability and preventing diabetes-related complications (Funnell, 2010). However, many individuals find the rather ad hoc nature of such management difficult to implement and sustain (Norris *et al*., 2002). As a result, theoretically underpinned, structured patient education programmes with elements of cognitive reframing have a high priority on the governmental healthcare agenda in the United Kingdom (Ellis *et al*., 2004). Several education programmes have recently been developed and these are discussed in the following section.

There is a clear need to ensure that people with LD are offered the same health promotion interventions as for the general population. The *Equality Act 2010* sets out the legal requirement for public services to provide reasonable adjustments at both service level and individual level for people with a disability, and that should include provision of accessible therapeutic support. Alongside this, positive examples of attempts to reduce inequity, for example in identifying and addressing barriers, have been acknowledged and disseminated

(Intellectual Disability and Health, 2019). In addition, Article 2 of the United Nations Convention on the Rights of Persons with Disabilities (2006) identifies reasonable accommodation to mean *"necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms"*. This can be interpreted within Article 25 which identifies the need for *"appropriate measures to ensure access for persons with disabilities to health services … [of] the same range, quality and standard of free or affordable health care and programmes as provided to other persons"*. In light of this a small number of studies have recognised the need for such interventions targeted at people with LD, which are discussed in the following section.

Diabetes and people with learning disabilities – barriers and support needs

People with LD experience a range of barriers to effective self-management and additional support needs when living with diabetes. These are often closely influenced by the environment of the individual, rather than being the result of internal dispositions and motivations. Three systematic reviews have been conducted which highlight the literature on the experiences of people with LD self-managing diabetes (McVilly *et al*., 2014; MacRae *et al*., 2015; Maine *et al*., 2018). An issue commonly discussed in these reviews is the role of care providers, including support workers and nurses. Adequate appropriate training was often described as insufficient and, in tandem with this, attitudes of care providers were occasionally barriers to self-management, for example through paternalistic approaches that limited the autonomy of people with LD (Hale *et al*., 2011; Dysch *et al*., 2012).

With regard to training, these reviews highlighted several studies where the diabetes knowledge of caregivers was described as limited (Cardol *et al.*, 2012b; Hale *et al.*, 2011; Rey-Conde *et al.*, 2005; Trip *et al.*, 2015), which was attributed to differing levels of experience and high staff turnover. It should however be noted that these studies described different levels of carer support, including residential support workers with basic training, and registered nurses with advanced clinical skills. In addition, duration of experience was not commonly reported. It is therefore a challenge to summarise training quality based on the current evidence.

Polarised attitudes of caregivers have been reported, with some reporting service users as ‘lazy’ (Rouse and Finlay, 2016) and taking a prohibitive approach to dietary control, and others recognising a need for a flexible approach in which changes such as medication adjustments and life events should be taken into account. This may reflect a need for consistency in staff training, although these findings are based on small samples and it is not possible to determine the extent of this issue. However, the flexibility of caregivers in Dysch *et al.* (2012), and the notion of negotiated autonomy described by Whitehead *et al.* (2016) provide a template for best practice in care, which could be incorporated into future staff training.

The issue of caregiver report as a barrier to self-management has been reported at a managerial and organisational level. Cardol *et al.* (2012b) reported the views of caregivers who had undertaken diabetes training at their own initiative, implying that this was not seen as priority training by their organisations. O’Leary *et al.* (2018) described the need for an organisational ethos of healthy lifestyle promotion within LD care organisations. It is therefore imperative that there is a cultural shift in the perceived need for diabetes training in care provision, and this must be directed from a policy level.

Further situational barriers have been reported. Shared living situations occasionally present frustrations for people with LD self-managing diabetes when their peers have unrestricted diets (Cardol *et al*., 2012a). Access to physical activity was also reported as a barrier where organizational resources prevented the availability of transport. In addition, psychosocial barriers have been highlighted, such as the frustration of people with LD at their dependency on caregivers for medication administration, and a perceived sense of social stigma over using insulin injections (Dysch *et al*., 2012). These feelings may contribute to a lower sense of self-efficacy, which may further impact upon successful diabetes self-management (Maine *et al*., 2017).

Perhaps the most significant barrier to self-management is the limited understanding of chronic illness and healthy lifestyles for people with LD. Participants made statements which indicated a lack of awareness of the seriousness of diabetes (Cardol *et al*, 2012a), and in several studies an understanding of healthy diet was limited to sugar consumption. Few participants described engaging in sufficient levels of physical activity. It was identified across studies that appropriately tailored educational resources were required but were not available, whether for people with LD or for caregivers. Recent studies have begun to develop and trial tailored education programmes. Taggart *et al*. (2017) adapted DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed), a structured education programme, for people with LD diagnosed with type 2 diabetes, and a second programme, OK Diabetes, is currently under study (Walwyn *et al*., 2015). Pilot data has been collected for a preventative diabetes programme aimed at reducing risk factors for individuals identified as at risk of diabetes (Dunkley *et al*., 2018), and a feasibility study delivering diabetes preventative education in two further education (FE) colleges in the UK was reported by Maine *et al*. (2019). These studies are at an early stage and there is as yet little evidence to support their efficacy. The programmes were theoretically informed and promoted psychical activity, and both were acceptable to users according to focus groups. Maine *et al*. (2019) reported challenges in the accessibility of untailored materials and the need for high support to use devices for measuring ambulatory activity, such as pedometers. However, the FE college setting was promising in terms of recruitment and sustained support. In the mainstream population, long term adherence to interventions is limited (Coates *et al*., 2017), and continued support from carers and supporters may be a necessity.

Services, supports and care coordination

In many countries, recent decades have seen a move away from institutional models to care and support based in the community (Simplican *et al*., 2015; Felce, 2016). The vast majority of people with LD now live at home with their family or live in supported accommodation in the community. As a result, they access universal health services, and such services may require additional support, assistance and information to assess, diagnose, treat and manage their physical and psychological health needs (Carey *et al*., 2016), including those associated with diabetes. Diabetes is often initially diagnosed and treated within primary care services when health screening is undertaken (Brown *et al*., 2017). Supporting people with LD to attend health appointments is important as there is evidence that accessing health screening leads to the identification of health conditions that when managed effectively improve health and quality of life (Bakker van Gijssel *et al*., 2017).

Some people with LD may require additional support to enable access to health screening and services (Williamson *et al*., 2017). This may involve assistance from families and support workers to attend appointment and help with providing relevant health information and history (Balogh *et al*., 2016). Attending health appointments can be stressful and cause anxiety for some people with LD. For example, bright, high stimuli waiting rooms can be a barrier to screening uptake (Williamson *et al*. 2017). Reasonable adjustments can be made to remove barriers that reduce access to health services. Many can be easily achieved and have a positive impact on health outcomes and care experiences (Tuffrey-Wijne and Hollins, 2014). They include, for example, the use of hospital passports, accessible health information, flexible appointments, and access to LD liaison nurses (Heslop *et al*., 2014). Accessible health information may be required by some people with LD to ensure that they better understand their diabetes or associated health condition (Chinn & Homeyard, 2017). Health professionals use a range of resources to support people with LD with diabetes to provide health education and information about their condition and how it can be managed to minimise the risk of complications (Taggart *et al*., 2013).

Some people with LD may present with more complex diabetes and co-existing health conditions that can result in complications that necessitate access to specialist diabetic services, usually within a hospital clinic setting to enable assessment, investigations and management (Balogh *et al*., 2015). Additional support and reasonable adjustments may be required to facilitate access to such settings. Learning Disability Liaison Nursing roles have been implemented in many acute hospitals to provide additional support for people with LD and their families or supporters when attending for assessment, investigations and treatments (MacArthur *et al*., 2015). Specialist learning disability health services have been developed in some countries, including the United Kingdom, to provide assessment, treatments, interventions, education and support for people with LD, their families and carers and other professionals (O’Reilly *et al*., 2018). People with LD may require access to learning disability health services at particular times when they have needs that require specialist care and support. LD health services usually comprise professionals including, psychiatrists, clinical psychologists, learning disability nurses, dietitians, occupational therapists, physiotherapists, speech and language therapists and social workers (Farrington *et al*., 2015).

To effectively manage diabetes at home and in residential and day care services, targeted health education and information may be required by people with LD and their families and care workers (Taggart *et al*., 2018). To ensure that this is effective and person-centred, co-production is required, whereby people with LD are at the centre of decisions about their health and treatment plans, thereby aiming to ensure that meaningful outcomes are achieved (Roberts *et al*., 2013). Given the range of health conditions, including diabetes, experienced by many people with LD, the coordination of care and health information exchange is required across and between care services and with the person with LD and their supporters (McNeil *et al*., 2018). Failure to ensure effective coordination and health information exchange can have a negative and detrimental impact on safety of care, health outcomes and quality of life (Glover *et al*., 2017)

Conclusions

This review has provided an account of the extant knowledge base on diabetes and people with LD, including current definitions and terminology, prevalence, support and educational needs, current interventions, and implications for services. Approaches to support diabetes self-management have been adapted for people with LD, but further, more robust trials are required to ensure that information and learning materials are appropriately tailored. In tandem with this, provision of education and care information must be carefully coordinated to ensure effective prevention or self-management of diabetes. Research should be undertaken to further explore preventative educational programmes across settings and to explore solutions which promote coordination between primary care services and care givers. For these changes to be effective, implementation and direction must happen at policy level.

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