



Review article

Diabetes in people with intellectual disabilities: A systematic review of the literature



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ABSTRACT

Objective: To present an analysis of the evidence related to the prevalence of diabetes in people with intellectual disabilities (ID), their experiences of their condition and treatment and those of their carers.

Materials and methods: A systematic literature review was conducted. A total of 22 studies exploring diabetes prevalence and 5 exploring views and experiences of diabetes in people with ID were identified and included. A narrative synthesis approach was utilised to amalgamate data extracted from the included studies regarding some 49,046 participants with ID and diabetes and 31 care professionals and family members across Europe, North America, New Zealand, Australia, China and Hong Kong.

Results: Prevalence rates of diabetes in people with ID were highly varied, ranging from 0.4% to 25%. 7 studies reported significantly higher rates of diabetes in people with ID than the general population. People with ID reported a basic understanding of diabetes and wanted to know more. Carers reported that they lack diabetes knowledge and do not routinely encourage diabetes self-management skills. Several studies neglected to report vital demographic information such as participants' level of ID (13 studies) and diabetes type (16 studies) and the quality of included prevalence studies was variable.

Conclusions: Further research in this field is required, notably prevalence studies which control for participant demographics and personal situations to obtain more accurate diabetes prevalence rates in this population group. People with ID and diabetes should be encouraged to participate in future research and we recommend exploring the feasibility of adapting current mainstream diabetes management programmes for these individuals.

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1. Introduction

The term intellectual disabilities (ID) is characterised by significant limitations in intellectual functioning and adaptive behaviours originating before age 18. People with ID typically display an IQ below 70 and limited conceptual, social, practical and adaptive skills (Schalock et al., 2010). A range of alternative terms are used internationally, such as learning disabilities (LD), developmental disabilities (DD) and, less commonly, mental retardation (MD), which essentially label the same condition. ID remains the most widespread, universally recognised term and will be utilised throughout this paper.

People with ID constitute 1–2.5% of the population in the Western world (Gillberg & Soderstrom, 2003). Studies from England (Emerson et al., 2012) and Australia (Wen, 2004) report similar prevalence rates of 2% and 2–3% respectively. It has been previously recognised that people with ID experience poorer health compared with the general population (Glover, Emerson, & Eccles, 2012) in addition to a higher prevalence of physical health conditions and significant barriers to adequate health care (Jansen, Krol, Groothoff, & Post, 2004). There is a paucity of research specifically targeting diabetes and people with ID, yet it is apparent that it is an area requiring further attention considering evidence suggesting people with ID are more likely to experience the major diabetes risk factors – poor nutrition; high fat, sugar and salt intake; high blood pressure; a sedentary lifestyle with limited physical activity and associated obesity (Bartlo & Klein, 2011; Ewing, McDermott, Thomas-Koger, Whitner, & Pierce, 2004; McGuire, Daly, & Smyth, 2007; Merrick & Morad, 2010; Merrick et al., 2004; Mokdad et al., 2003; Sohler, Lubetkin, Levy, Soghomonian, & Rimmerman, 2009). The worldwide prevalence of diabetes is rapidly increasing, as is the number of people dying as a consequence of diabetes-related complications (WHO, 2006). Furthermore, a 14% increase in the number of people with ID by 2021 is predicted (Emerson & Hatton, 2008) with life expectancy advancing (Bittles et al., 2002). Diabetes is, therefore, impacting on the lives of people globally and evidence points to increasing complications and risk. People with ID are more likely to experience the major risk factors associated with diabetes and are living longer. As a consequence, appropriate access to healthcare and additional resources is required yet research focusing on the distinct needs of this population remains limited.

This paper presents findings from a systematic review of the current research evidence related to diabetes and people with ID. The review systematically evaluates data obtained from a total of 27 studies. It is envisaged that examining the available literature will identify gaps in evidence which can be used to inform further research and clinical practice in this field.

1.1. Systematic review questions

1. What is the prevalence of diabetes amongst people with ID?
2. What are the views of people with ID on managing their diabetes and the service they receive?
3. What are the views of carers of people with ID and diabetes regarding diabetes management and the current service provision?

2. Materials and methods

2.1. Search strategy

The primary literature search was carried out between October and November 2013 by the lead researcher. A comprehensive computerised search of the literature was conducted using 14 English language databases: AMED, CINAHL,

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