

The Experiences of Self-Management of Diabetes for Adults with an Intellectual Disability

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Diabetes mellitus is a group of metabolic diseases characterized by chronic hyperglycaemia resulting from defects in insulin secretion, insulin action, or both which usually occurs when the pancreas is not able to create enough insulin. Diabetes is a disease that seems to afflict individuals with an intellectual disability at a higher rate than those in the general population without an intellectual disability, with studies proving that those with an intellectual disability tend to have a higher prevalence of chronic health conditions compared to those in the general population. Intellectual disability is a form of developmental disability that can be characterised by significant limitations in both intellectual functioning such as reasoning, learning and problem solving and in adaptive behaviour. It usually results in an impairment or reduced ability to understand new or complex information or to learn new skills.

Leading the care of those with an intellectual disability in Ireland is the Registered Nurse Intellectual Disability (RNID). The RNID plays a prominent role in working in tandem with the service user (the term used for those with an intellectual disability availing of care from the RNID in Ireland). Changing demographics, renewed movement into community settings and newly emerging health care needs among people with intellectual disability mean that the delivery of care in all aspects of people's lives is central to the role of the RNID. As such the RNID is a vital component in ensuring and aiding towards the successful self-management of diabetes for those with an intellectual disability.

The research question used in the research project was "What is the literature view on the experiences of self-management of diabetes for adults with an intellectual disability?". This question was formulated using Wakefield's guidelines and using the PEO (Population, exposure, outcome) format. A search was carried out using the University's database system to source relevant literature on the chosen topic. Three separate literature databases were used – CINAHL, PsychINFO and MEDLINE. These databases were used to search for any literature in the area of nursing and of behavioural sciences that would have been relevant to the research aim. The inclusion and exclusion criteria included limiting the date of publication between January 2014 and September 2019 to ensure the literature being reviewed was correct and up to date. Other filters used included: adults between the ages of 19 and 44 with a diagnosis of disability, diabetes onset through genetics or lifestyle, primary literature resources and

geographically relatable literature sources. This left 862 results which were evaluated by the author until just five relevant articles remained. The author then used the CASP tool to evaluate and critique these articles to ensure suitability.

Upon critiquing of the articles, three prominent themes found throughout all of them emerged – education and knowledge in self-managing diabetes, the importance of autonomy and person-centredness and support and training from staff in practice for the individual with ID and diabetes. Education and knowledge is a key component in the art of successful self-management of diabetes. Achieving a mastery of knowledge in relation to diet, medication and monitoring and diabetes knowledge can lead to a level of competence in these areas, which in turn can see the individuals speak with confidence about self-management of their condition as well gaining knowledge through independent learning, group learning or through information from accessible information. Lack of education or knowledge may obstruct the self-management of the condition as well as resulting in confusion in relation to diet, poor understanding of exercise and having to depend on staff for support.

Autonomy and person-centeredness is an essential concept of the relationship shared between staff and service user and plays a key role in ensuring a positive level of care that allows the individual to self-manage their diabetes successfully. Adequate autonomy and person-centred care can result in a better standard in self-care levels, with motivation and support from staff empowering the service user to greater levels of independence. Mastery of self-management through autonomy has shown to be dependent on the relationship between the individual with diabetes and staff who have the knowledge to successfully facilitate the management with them. To negotiate a greater level of autonomy, the goals must centre around more independence for the individual with diabetes and make sure the RNID balances oversight and autonomy by viewing self-management tasks being carried out but ensuring they do not take over the activity themselves.

Staff or key workers providing support to individuals with an intellectual disability is pivotal in the process of engaging and aiding the self-management of diabetes. An individual's level of intellectual disability, their comprehension and their communication skills can impact on their understanding and acceptance of their diabetes diagnosis which can then in turn have an effect on their treatment regime, diet, exercise and medication use. An active and positive relationship between staff and the person is imperative and can be characterised and managed through the negotiation of autonomy between both parties.

There is a need to incorporate more training and support for both the individual and staff tasked with the self-management of the condition. Individuals often acquire information on self-management independently which in turn may lead to self-educating themselves through the process of trial and error, which of course may be detrimental to the health status of the individual. Having the service user attend mainstream diabetes information clinics may be overwhelming which is why the DESMOND (Diabetes Self-Management for Ongoing and Newly Diagnosed with Intellectual Disabilities) was developed by researchers at Ulster University, United Kingdom. This program simplifies the mainstream information sessions making it easier for intellectually disabled individuals of all cognitive abilities to learn more about their condition. I would recommend that a similar simplified program be developed in Ireland as currently no such program exists. While the HSE offer an information leaflet on self-management of diabetes, it is not available in an easy read format which makes it not very useful for those with an intellectual disability as they may not comprehend the details found within the document. This is an aspect that needs to be looked at as an easy-read leaflet or document may provide the necessary information to the service user which may discourage them from self-managing through trial and error.

Overall, while there are numerous documents and guidelines in place both domestically and internationally additional research into autonomy and person-centeredness is needed as the needs of the service user are constantly changing and autonomy must change with it to ensure the independence of the service user doesn't go awry. Structured education to improve health literacy and diabetes knowledge in people with ID is required, together with training for caregivers which leads to a culture of nurturing autonomy.

The evidence gathered clearly shows that diabetes self-management in the intellectual disability community requires more evidence based research, readiness of knowledge to be passed along to the person in relation to self-managing their condition and constant staff training in order to ensure that the correct supports are in place to successfully self-manage diabetes and ensure the safety of the individual at all times.