Delivering diabetes care to people with intellectual disability

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Typically, people with learning difficulties due to intellectual disability face a variety of daily challenges, and require continual support from specialized carers. If they are affected by a chronic medical condition, such as diabetes, people with intellectual disability require coordinated support from diabetes-aware carers and informed healthcare providers. The authors examine the challenges faced by people with intellectual disability, offer advice to carers and healthcare providers, and describe a web-based resource designed to enhance such a collaborative approach to diabetes care and management.

Intellectual disability occurs in about 3% of the general population;[1] diabetes in around 6%. Sometimes the two occur in the same person. According to the definition of the US American Association on Mental Retardation, for a person to have intellectual disability, he or she must have an IQ below 70, have problems in at least two areas of daily living, and have had the disability since before the age of 18 years.[2]

We do not know the exact prevalence of diabetes in people with intellectual disability, but it is probably higher than in the general population. Type 1 diabetes is up to 35 times more common in people with intellectual disability compared with people without intellectual disability.[3] Type 2 diabetes is also common, but there is no reliable estimate of its prevalence in this group.

Type 2 diabetes

The factors leading people with intellectual disability to develop type 2 diabetes are the same as those in other people: family aspects, old-age, obesity, lack of physical activity. However, people with intellectual disability appear to be at increased risk. We know that obesity is almost four times more common in people with intellectual disability compared with the general population.[4] People with intellectual disability often have low social status, which is also a risk factor for type 2 diabetes.[5]

> **Limited funding often prevents people with intellectual disability from receiving adequate support.**

Nutritional therapy and physical activity are often referred to as cornerstones of diabetes care. While physical activity has been shown to benefit people with intellectual disability, it is often difficult for them to make this part of their daily life. Many people with intellectual disability need the support of a carer while they

exercise. In most settings, inadequate staffing levels, due to limited financing in the medical and mental health sectors, prevents people with intellectual disability from receiving this support.

Communication

Frequently, problems of communication arise between healthcare providers and people with intellectual disability. Unfortunately, many healthcare providers are unaware or insensitive to the needs and feelings of people with intellectual disability. Research has indicated, for example, that people with intellectual disability complain about healthcare providers who raise their voice, do not explain procedures, and treat people in their care as if they were 'stupid'. In spite of their cognitive limitations, people with intellectual disability are often able to perceive when a healthcare provider 'pretends' to understand even if this is clearly not the case.

Respect for people despite their intellectual disability is crucial if healthcare providers are to forge effective relationships with people in their care and thus ensure optimum levels of care. The focus of common complaints, such as healthcare providers not listening to a person's opinion or not giving them time to reply, represent barriers to effective care.

> **Respect for people with intellectual disability is crucial to ensure optimum care.**

Communication can be improved if healthcare providers adjust their approach to interacting with people in their care. The following advice to healthcare providers has proved effective when working with people with intellectual disability:

- avoid jargon and adopt language that is familiar to the person
- use clear and direct speech
- use age-appropriate style and vocabulary
- use real and familiar examples to explain concepts
- expect a response; wait at least 10 seconds
- use body language, signs, gestures, facial expressions, and demonstrations.

Diagnosing diabetes

In order to diagnose diabetes and review care, healthcare providers working in a laboratory or clinic must carry out blood and urine testing. This can prove difficult in people with intellectual disability. If the person has not received appropriate education on blood testing, the clinic should be contacted prior to his or her appointment. Arrangements should be made for experienced staff to carry out the collection of blood and, if necessary, urine.

This work will be made easier if people with intellectual disability are prepared for the procedure before hand; the more knowledge they have, the smoother the process for all involved. Carers and healthcare providers should practise each step of blood testing with the person with intellectual disability. They will then be able to see the person's levels of ability. Having established this, the healthcare provider will be able to work on the more difficult steps.

Diabetes management

The complexities of diabetes management are intensified in people with intellectual disability. Generally, the person's carer is in charge of the daily diabetes management. All carers, both families and paid carers, should have good diabetes knowledge and skills.

> **All carers – families and paid carers – should have good diabetes knowledge and skills.**

Many people with intellectual disability live in shared accommodation, often with people who have a similar disability. In shared housing, there is frequently a high turnover of staff, which complicates the provision of care to people with diabetes. Therefore, an individual management plan should be set up for each person with diabetes with the help of a healthcare provider. Carers need to be equipped with a list of each person's diabetes needs, including specific information on blood glucose testing, nutrition, and emergency procedures.

In many cases, carers are extremely apprehensive when working with people with diabetes; carers' perceptions of their own ability to manage diabetes are often negative. As well as basic diabetes education, carers need good communications networks with healthcare providers and robust systems of support from healthcare services.

Advice to healthcare providers

When providing diabetes education to people with intellectual disability, it is essential that healthcare providers establish a sound personal relationship. This may require high levels of empathy and patience on the part of the healthcare provider; in many instances, people with intellectual disability are wary of strangers.

With adequate and appropriate education, people with intellectual disability can achieve some degree of autonomy and thus radically improved quality of life. A key task of healthcare providers is to identify each person's preferred form of learning. A familiar and trusted person might be in the best position to do this, and either offer appropriate education him or herself, or offer advice on the person's learning.

Effective learning, in any field, is enhanced by frequent repetition of data and concepts. This approach is particularly important in people with intellectual disability.

> **Effective learning is enhanced by frequent repetition – even more so in people with intellectual disability.**

Web-based resource

To support improvements in day-to-day diabetes care and management, we recently developed a website for people with intellectual disability and diabetes (see web address below). The website also offers supplementary material for diabetes healthcare providers.

The site is divided into two main menus: one for people with disability (in plain English and large print); the other for carers. The content is based on recommendations made by people in the disability sector, is free of jargon, emphasizes effective communication, and acknowledges individual needs.

One of site's key aims is to enhance cooperation between people with diabetes and intellectual disability, their carers, and their healthcare providers. One section contains a management plan that can be printed and individualized in consultation with the person with diabetes, their carer, and healthcare provider. Details covered in the management plan include:

- type of diabetes
- ranges for low, ideal and high blood glucose levels
- level of risk for hypoglycaemia
- probable symptoms of hypoglycaemia for each person
- emergency procedures.

Important specific needs and characteristics of each person's diabetes can be documented on the management plan. This information is very useful for people with intellectual disability given the high numbers of carers in shared housing.

A study of the impact of the website suggested carers had benefited in their work with people with diabetes. Feedback on use of the resource included: enhanced diabetes management skills (taking blood glucose measurements, for example); improved knowledge on seeking professional advice; improvements in communication with other carers.

Summary

The many and varied tasks involved in the daily management of diabetes are complicated in people with intellectual disability. Furthermore, people with these conditions often fall into a low-resource group with limited care facilities. It is essential that these people receive the coordinated support of carers and healthcare providers. We have seen that tangible improvements in care can be made using simple tools, and applying minimal adjustments in approaches to communication. However, the disability sector remains critically under-funded in almost all countries. Further studies are needed into cost-effective measures to improve care in people with intellectual disability and diabetes.

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QCIDD supports people with intellectual disability by research, teaching and clinical activities. The online support described above can be accessed at: www.som.uq.edu.au/research/qcidd/diabetes/index.htm

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