

The challenges for families managing an adolescent with an intellectual disability and type 1 diabetes

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KEY WORDS

type 1 diabetes; intellectual disability; independence; responsibility, parents, families

ABSTRACT

Objective

This paper describes the experiences of two families caring for their adolescent sons who have type 1 diabetes (T1D) and an intellectual disability.

Design

This paper arises from a larger study and reports on the findings from four parents, (two couples), who have adolescent sons with both type 1 diabetes and intellectual disability. Case study analysis of these interviews gave a more in-depth understanding of management of these dual conditions from the perspective of the parents.

Setting

The interviews occurred in the parents homes.

Subjects

Family one consisted of a mother, father, and three children aged 16 to 20 years. Family two comprised both parents and four children attending secondary school. At the time of the study all siblings were living at home. The two adolescent men with intellectual disability and T1D were 19 year old, still living at home and attending sheltered employment.

Main Outcome Measures

This paper describes the experiences of two families caring for their adolescent sons who have T1D and an intellectual disability.

Results

Independence was the major issue. Obtaining independence was hindered on several fronts: having an intellectual disability and having to manage T1D concurrently, and the short and long-term effects this management has on the family now and in the future.

Conclusion

The complex management of T1D coupled with intellectual disability makes independence more difficult to attain for these adolescents. The parents in this study accepted that full independence may not be possible for their sons and voiced concern for their future wellbeing.

INTRODUCTION

People take on the role of parenthood with the understanding and acceptance that they will be responsible for the care and development of their offspring until they are able to function independently. It is important to understand what effect it has on families when total independence is unlikely because the child is diagnosed with a chronic disorder. This paper describes the challenges of caring for two adolescents who have intellectual disability and type 1 diabetes mellitus (T1D).

A person is regarded as having an intellectual disability if they have a low intellectual functioning and significant limitations in adaptive behaviour and the condition is present from childhood (defined as age 18 years or less). The Australian Institute of Health and Welfare (AIHW) have stated that the disability policy currently in Australia supports a multidimensional approach that includes assessment of the need for assistance as one of the components and classifications of disability (Australian Institute of Health and Welfare 2003). The causes and range of intellectual disability are many and varied, and people may have a concurrent syndrome, such as, Down syndrome.

T1D is described as the destruction of beta - cells by an autoimmune process that leads to the dependence on exogenous insulin (AIHW 2009). In Australia, the diagnosis of diabetes has risen largely because of the increase in the prevalence of Type 2 diabetes although the prevalence of T1D is also on the rise (AIHW 2009). Catanzariti et al (2009) indicate that the incidence of T1D has increased from 19.8 in 2000 to 23.4 per 100,000 in 2006. This incidence was higher in boys aged 0–4 years and 10–14 years than in girls of a similar age. The occurrence of T1D among 0–14-year-olds in Australia is high compared with data from many other countries. This rise in incidence cannot be explained simply by changes in genetic susceptibility.

There is a paucity of research about the combined effects of T1D and an intellectual disability. Roizen (1996) and Smith (2001), indicate that people with Down syndrome, experience other disorders including endocrine disorders, such as, T1D and Type 2 diabetes mellitus (T2DM). Lammer and Welmann (2008) indicate that people with Down syndrome have an increased risk of developing autoimmune diseases compared with the general population. Gillespie et al (2006) concluded that this was because diabetes-associated class II haplotypes are increased in children with Down syndrome.

The management of T1D places heavy daily demands on people with diabetes and their families. These demands include insulin injections; a dietary plan; balancing exercise; food intake and insulin dosage; and/or urine and blood testing (Meltzer et al 2003). However, maintaining a healthy range of blood glucose values is more complex than simply balancing the three major elements of management. T1D has acute complications, the most common being hypoglycaemia, which can cause seizures and loss of consciousness. Another may be hyperglycaemia leading to ketoacidosis, which is a serious life threatening condition (Meltzer et al 2003). People with an intellectual disability might not be able to identify the symptoms of either hypo or hyperglycaemia in the same manner as those with diabetes who do not have this impairment. People with T1D are susceptible to long term complications including blindness, kidney failure, varied neuropathies, peripheral vascular disease and foot problems. These complications occur at a much younger age in those with T1D (AIHW 2009). The management of T1D may be further complicated when the patient has little understanding of the need for a treatment regime or dietary restrictions as in the case of a coexisting intellectual disability.

METHOD

Research design

This paper reports on the findings from four parents (two couples) who have adolescent sons with both T1D and intellectual disability. Case study analysis of the interview data was completed and themes were uncovered.

Case study analysis allows for exploration of the complex phenomenon of caring and is a comprehensive strategy for exploring multiple realities (Baxter and Jack, 2008; Jones and Lyons, 2004). This approach is frequently used to explore cases of interest in an all-inclusive and meaningful manner (Luck, Jackson and Usher 2006). Case study analysis allows for a more in-depth understanding of management of these dual conditions from the perspective of the parents.

Setting and sample

Participants were recruited from two self-help support groups - The Juvenile Diabetes Foundation and Diabetes Australia and snowballing. Family one consisted of two parents and their three children aged 16 to 20 years. Family two comprised both parents, and their four children whose ages ranged from 12 to 19 years. Both of the adolescents with intellectual disability and T1D were males 19 years of age, still living at home and attending sheltered employment. Both families lived in Sydney, New South Wales, Australia, one in the inner city and the other in the south west. At the time of the study all siblings were living at home.

Data Analysis

Interviews were audio taped and transcribed verbatim. The transcripts content were analysed using both manifest and latent content (Berg 2007) and key issues were uncovered.

Ethical considerations

The Human Ethics Review Committee of the University of Western Sydney granted ethical approval. Participants were given an information sheet about the study and consent was obtained before interview. All transcript data were de-identified and the names of participants were kept separately from the interview transcripts and tapes. Although, at times, the interviews raised some distressing issues, none of the participants required the interview to be terminated or were referred for counselling. In keeping with confidentiality agreements, the participants in this study are referred to using pseudonyms. The first author conducted the initial interviews. The other authors only had access to de-identified transcripts.

FINDINGS

The parents highlighted the key issues from their perspectives of living with their adolescent son. Adolescence is generally accepted as a testing time as family members begin to question and juggle parental involvement against the child's developing autonomy and desire to assume responsibility for their own care (Palmer et al 2004). Often, having an adolescent son who also has T1D and a moderate to severe intellectual disability, presents a unique challenge for parents beyond that experienced by parents of sons with only one of these conditions.

Issues

The overarching issue mentioned by parents was their son's independence. The definition of independence used in this paper is the desire to be autonomous with self-determination, decision making and taking a greater control of one's own affairs. Independence as a concept was viewed as a point on a continuum with dependence at one end and independence at the other. The effects that these two conditions have on the two families are profound because the ability and responsibility for the management becomes shared among other family members.

Independence and Intellectual Disability

Individuals who have an intellectual disability strive for independence in much the same way as everyone else. An intellectual disability, as well as, T1D was seen as a double blow. One parent stated that when her son was diagnosed with T1D she was:

stunned, because aside from his diabetes he has a lot of other medical and physical problems so it was just another one on top of all the rest (P)

Another parent shared comments made by others:

because Down Syndrome is obvious, people just say oh my God poor thing!, and he has to cope with both, sort of reaction. . . it's a double whammy and they feel sorry for X and us (K)

The parents explained that their child needed support in many activities of daily living as a result of his intellectual disability. The intellectual disability crossed over into the area of diabetes management. Even though each adolescent had some understanding of the routine and equipment requirements for blood glucose testing, they had little comprehension of the implication of what that blood glucose level meant.

he'll never be able to live independently and even in group homes, . . there's always got to be somebody, an adult person there because Y's got no idea, no idea whatsoever about his diabetes or even, I mean he'll turn on the machine, he knows what to get out, all of the equipment, but he doesn't actually know how to draw the insulin or how to do his blood tests (J)

Independence and Diabetes Management

The management of T1D can be challenging for everyone. Both of the families in this study had already experienced the usual reactions of grief and loss, such as shock and denial, to having a child with an intellectual disability. When they spoke of receiving the diagnosis of T1D, they said:

we're quite good at crises we sort of deal with them, you learn all about it and understand it all and do it all and it isn't till later the full impact sort of sits with you, like the reality (K)

When diabetes is coupled with an intellectual disability, many cope by including other people, both inside and outside of the family in assistance and responsibility for the day to day management. The following example illustrates the range of individuals and organisations involved with their adolescent's care.

it means that one or other of us has to be [there], or the kids... I mean... we've been away for weekends and either N or her older brother B will do it for us or friends might, or he goes to school camp and the teacher's aid does it all, fantastic they are, very good, respite care people do blood tests and if they go on camp, ...but it means ... everything becomes a bigger deal (P)

Parents indicated that dependence was caused by the T1D more so than the intellectual disability.

If X didn't have diabetes and just had Down Syndrome well his life would be somewhat different I think, and in so far as his independence is concerned, I mean there'd still be issues about independence, but it wouldn't be based around his exercise, food intake and so on, and if he was with some friends and went to town and they were going to stay on and whatever, well he'd just ring up and that'd be fine (P and K)

Having T1D meant that independence was restricted, and both families grappled with the dilemma of whether to keep their children safe by attending to all of their needs personally or to allow them to take certain risks in the pursuit of learning and independence.

Our hope is that you know he'll be in a situation where he will be able to be independent. I think it's a little bit of tug of war between letting go totally and keeping him but the problem with keeping him home is that he loses that independence but he has other securities so I think it's a balancing act as to what is more important at any particular time..., because of his other disabilities, management of the diabetes is a major problem for him so he needs somebody else to manage it (P and K)

The parents described some physical complications that added to the cognitive impairments.

He's just beginning to actually have enough oomph in his fingers to use the pen [injecting device for insulin] [it] takes quite a bit of oomph to push the thing in, well he did it this morning quite well but I wouldn't trust him to dial up the right dose or anything (J and M)

The other parents also found that their son had difficulty with the syringes and paraphernalia.

His right hand, particularly his thumb, he can't do the blood tests correctly, he can't possibly do the insulin you know, like draw up the insulin (J and M)

Both parents reported their sons' lack of understanding regarding the clinical symptoms of diabetes. One parent was asked whether her son would be able to help himself out of an impending hypoglycaemic episode.

Interviewer: He doesn't carry jelly beans with him?

No, he wouldn't sort of correlate, probably eat them before. K)

The other parents agreed.

Because he can't manage it himself, and he doesn't recognise the symptoms himself, he could be having, a high or a low, he doesn't know what it is, because he doesn't know what it is he can't take the appropriate action so if people around him also don't recognise what's going on, they could mistakenly take him for something totally different (P)

Each parent told of times when the spontaneity of life was hampered by their sons' diabetes. These examples show how it is not just their sons' independence that is curtailed but theirs as well.

You've got to take it [diabetes management] into account when you're planning stuff.

X is fairly easily distracted by things that turn him [on], particularly arcade games. He was working at a cafeteria and he had to walk across the park to the end of [a busy road] and wait for the bus there and catch the bus down [this busy road]. He's got to be home to get his afternoon tea... come about six o'clock he still wasn't home... he was found at the bus stop at [this busy road] sort of on the verge of a hypo, so you know that's the worry (K)

There were also positive aspects described by both sets of parents. Their sons adapted to the routine of blood tests and meals well.

talking to people, with so called normal teenagers, it seems in some ways easier, X really likes routine, and he really is quite compliant about things...I mean we would wake him up and make him have breakfast where if you did that with a normal 19 year old they'd tell you where to go (K and P)

Independence and Responsibility

The families described the necessity for others, both inside and outside the home, to be involved in the care and to assume some responsibility for the management of their son's T1D. Their siblings have been involved in this management for a long time.

..there're situations where we're not home but he's home with his brothers and sister... from a very early age they were taught how to manage the blood test and the drawing up of the insulin and give the injection, they have to be able to recognise [and know] what to do about a hypo (J and M)

The parents always bear at least part of the responsibility for the management of their son's diabetes. Over the years they have had to educate various carers and teachers, and this continues even after their child has left home as the following example shows.

When he went to [residential facility]...the phone calls and, the fear... if they were cooking something new, they'd ring up and say we're having honey chicken tonight, how will that affect Y or we're going to such and such a place and I'd just say that's fine. He was there for 5 years so they got the hang of it, it wasn't the same people all the time, and we had to train a couple of different people (J and M)

The need to have a responsible adult on hand was raised by both sets of parents. This has implications for possible future residential accommodation, employment prospects and social activities for their son. The following example shows the reluctance of others to accept responsibility for the wellbeing of a person with both an intellectual disability and T1D.

there's virtually no one who will, who has volunteered, or we've been game to ask, who will have X overnight (K and P)

Thus, these parents remained ultimately responsible for the care of their sons even though the sons were becoming young adults.

DISCUSSION

Gaining independence for many people who have intellectual disability can be a challenge in itself, but it can be further complicated for people who have T1D. Independence is contingent on the ability to understand the disorder as well as to be able to perform the skills necessary for responsible diabetes management.

Parents teach their children to become independent in preparation for the day when they leave the family home and start their own life (Palmer et al 2004). One of the major issues arising from this study was the families' acceptance that total independence for their sons may never eventuate.

Obtaining independence was hindered on several fronts. This included having an intellectual disability in the first instance, having to manage T1D concurrently, and the short and long-term effects of the management on the family now and in the future.

People with an intellectual disability are encouraged to be as independent as possible with their activities of daily living. The autonomous performance of activities of daily living skills empowers an individual and assists them to be included and valued in the community. This paper shows that independence is complicated by the presence of T1D. The carers' role becomes more complex because of the need to manage both the treatment regimes as well as the age-specific developmental tasks.

The parents interviewed in our study did not emphasise the burden of caring for their sons or the effect that this caring, had on their health. By contrast parents, in a study into intellectual disability, did describe the extra burden they felt in the management of their children and their need for support from external services (Maes et al 2003). Bourke et al (2008) explored the impact of Down syndrome on the physical and mental health of mothers. They found mothers experienced poorer mental health and required more support in behavioural management. Wang et al (2007) found morbidity increased in those with intellectual and developmental disability. The incidence of cardiovascular, neurological, visual and hearing impairments increased with age, thus adding to the burden of care.

The effect that a child with a disability has on a family unit naturally varies from family to family, and it varies according to each stage of the family life cycle. Adolescence is a key time when families may experience disruption as their children strive for independence and begin to make choices for themselves. These challenges are compounded for adolescents who have a disability and their families (Spear and Kulbok, 2004). Schneider et al (2006) found families face additional challenges with their disabled children during adolescence. They found it is important to balance the needs of all of the family members. However, it is

difficult for families because they are often fighting for the rights of their disabled children or are involved in their activities. At the same time the siblings require parental attention and this can have a negative effect on the cohesiveness of the family. The families in this study have the usual challenges of adolescence and the added challenges associated with disabilities and chronic health problems.

CONCLUSIONS

Parents play a vital role in the care of their children with T1D and an intellectual disability. It is important that carers be seen as equal partners with health professionals. Supporting the carers thus requires commitment from health professionals, who can act as enablers and facilitators. This support involves implicit recognition that the carers are the ones who are actually doing the caring fulltime. When offering support, it is useful to know that the type of support will vary between carers.

RECOMMENDATIONS

- Parents have an extended burden of caring for their child with both T1D and an intellectual disability and they should have access to appropriate respite to help them manage this complex task.
- Workers in group homes and schools should be given access to diabetes management education.
- Health professionals should be provided with access to education programs that provide information on intellectual disability, working with families and managing chronic health issues.

LIMITATIONS

A limitation of this study is the small sample size. As with all qualitative research, it cannot be generalised to the wider population of people with intellectual disability and T1D. However, this small study does point to the necessity of further research into this area.

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