

Diabetes and Intellectual Disability – Perceptions from People with Disability and their Supporters

See also <http://www.sph.uq.edu.au/diabetes>

ABSTRACT

Background: People with intellectual disability who have diabetes have few resources for themselves or their carers. There are multiple health issues present. The objective of the project was to describe the perceptions and experiences of living with diabetes as told by people with intellectual disability, their families and support staff.

Methods: The project was a qualitative semi-structured interview study, conducted in southeast Queensland, Australia. There were 67 people involved - adults with intellectual disability (9), family of adults with intellectual disability (8), paid support staff of adults with intellectual disability (31), service co-ordinators (12), health professionals (6) and a worker in the sector (1).

Focus group discussions were held with the participants. Their perceptions and experiences of living with and managing intellectual disability and diabetes were recorded and the themes of the discussions studied.

Results: The findings revealed a number of shortcomings in relation to diabetes care in a population of people with intellectual disability and their families and support staff. There are higher than average support needs when diabetes is present. There is resentment at intrusion in their lives by diabetes from people with disability. There are feelings of fear and insecurity about diabetes in families and support staff. Families and support staff feel that generally they lack knowledge and also lack support from their organisations to manage both the intellectual disability and the diabetes.

Conclusion: The general lack of confidence and knowledge about diabetes makes it difficult for people with intellectual disability and their families and support staff to function in an effective and satisfying way. There is a need for guidelines.

KEYWORDS: diabetes; disease management; education; focus groups; interviews

BACKGROUND

There is a considerable number of people with intellectual disability (PWID) in any population - about 2.7%¹⁻³. There is also a considerable number of people with diabetes mellitus (DM) in the general population – about 7.2%⁴. It is a major and growing health problem. Diabetes affects about 1 in 14 adults and is involved in 1 in every 13 deaths. The number of adults with the disease has trebled in the last 20 years⁵.

There are some people who have both intellectual disability and diabetes, of whom the prevalence is not known, and these people, their families and their support staff are the focus of this paper.

People with intellectual disability (ID) experience poor health outcomes, whether or not they have diabetes⁶. They have higher health needs than the general population and these needs are often both unrecognised and are unmet⁷. They have a life expectancy up to 15 years lower than the general population⁸. This appears in part to be due to higher prevalence of preventable, sometimes chronic diseases, including diabetes⁹.

The exact prevalence of diabetes in the population of people with intellectual disability is likely to be higher than in the general population, although estimations have been made¹⁰⁻¹⁴. Type 1 DM is thought to be up to 35 times as common in people with ID (5) and Type 2 DM is also common¹⁵.

Diabetes is a disease that has been extensively studied. It continues to be extensively studied. Even so, in the general population, studies are finding that a large proportion of elderly people with DM are not receiving care in accordance with published guidelines¹⁶. There are guidelines to DM management that are easily available, but morbidity and mortality statistics continue to increase.

Little research has been done for people with intellectual disability about this part of their health care. A search of the literature reveals that there is scant information available – 10 papers were brought up under the search terms of “diabetes and intellectual disability / mental retardation” in Medline. Most were about children, one was a case report and all others mentioned diabetes only in passing. One

demonstrated a decreased likelihood of chronic diseases, for example diabetes, in the population of people with intellectual disability ¹⁷.

The presence of diabetes in the lives of people with intellectual disability means increased complexity in lives generally already complex. Diabetes is a chronic disease, which means it is one that is ongoing, cannot be cured and is associated with change, often worsening over time ¹⁸. When both intellectual disability and diabetes are present, there may be multiple health issues to deal with. There are various management and lifestyle challenges. The support needed for people with intellectual disability and their families and support staff for the management of diabetes has not been clearly determined.

In the general population, patients can become good self-managers of a chronic disease such as diabetes and then have lower needs for support. In doing so, they can have some effect on the control of their symptoms themselves. There are areas of influence that it is claimed, determine the success of this management procedure ¹⁹.

- the patient – at the centre
- the family
- clinical expertise
- support received at work or school
- community wide environment
- wider policies that influence support.

These areas of influence are not as straightforward or positive for people with intellectual disability and their families and support staff.

- the **patient** with disability is not alone at the centre – support staff are often needed
- often **family** influence is substituted by paid support staff influence, and for full time support this may be three lots support staff in one day ¹⁴.
- **clinical expertise** often has the added complications communication difficulties and frequently inadequate histories ^{20,21}.
- support received at **work or school** varies

- **community** wide acceptance of people with intellectual disability is limited^{22,23}
- **wider policy** issues influence the group with ID more than the general population – their standard of living often depends on funding packages from Government agencies.

In summary, influences that affect the success of management of diabetes in the general population are more often more complicated for this population.

We did not know at the beginning of this project whether the areas of influence that support a person with diabetes management were the same for the general population and the population of people with intellectual disability. We considered from our experience at the Queensland Centre for Intellectual & Developmental Disability (QCIDD) that DM in adults with ID tends to be poorly managed. (QCIDD provides clinical services to adults with intellectual and developmental disability). This paper aims to document the attitudes to the management of diabetes in this population and the concerns faced by all.

We sought to determine whether the barriers to the effective management of diabetes are present in both population - the general population with diabetes and in the population of people with intellectual disability and diabetes. We wanted to find if any participants in our discussion groups had found solutions to those barriers. We wanted to determine what aspects of diabetes care work well in this population. We ultimately wanted to develop a format for distributing that information to others in the disability community.

METHOD

Most of this study was carried out in the southeast part of the state of Queensland, Australia. The region has a total population of 2.5 million people and accounts for 12% of the Australian population. Participants were from city and semi-rural regions. One teleconference was done to tropical north Queensland.

To be included in the study the participant had to be a person with intellectual disability and diabetes or be involved in the care of someone with those attributes. The definition of having an intellectual disability is that of a person with an IQ of less than 70 who needed assistance in at least two facets of daily living^{24,25}. A caregiver who gives the assistance was defined as the main person helping with activities of daily living. This person also advocates on behalf of the person with disability.

A definition of diabetes was not possible to enforce as selection criteria in this study. We accepted the assurances from people with disability and also from the families and support staff that the people they cared for did have diabetes. We asked people if they knew what type of diabetes they had or the person they supported had. Nearly everyone was confused by this question, as they were unaware that there were different types of diabetes.

We designed the tool used for data collection in this study as a semi-structured interview in order to give some direction to the focus groups discussions. We asked a person with intellectual disability who also has diabetes to help us with the design. We needed the wording to be clear and to elicit all the information it was possible to get, particularly with people with intellectual disability. We needed to repeat the same format with the families and support staff, for the sake of comparison, so a strongly structured tool would have been unsuitable. We carried out the discussions in both individual settings and focus group settings.

PARTICIPANTS

A researcher on our team with many years of experience in the disability sector invited people to participate in our convenience sample discussions. She contacted 150 relevant organisations. This took 147 phone calls, 32 emails, 20 letters and 13 faxes – a total of 212 attempts at communication.

The 150 organisations we contacted contributed 24 people to the project, resulting in a 16% success rate from them. About 3 attempts at communication were needed for each participant. Sixty-seven people agreed to participate in the discussions.

The nine people with intellectual disability who eventually participated had a range of communication abilities. Three were living at home with their families but most (six) were in supported accommodation.

There were 31 support staff, 8 family carers, 12 service co-coordinators, 6 health professionals and 1 person whose occupation was not recorded in the focus group discussions. We had 33 face-to-face interviews and 4 telephone interviews and 2 teleconferences. There was one practice interview with a PWID with diabetes.

The researcher asked each PWID at the beginning of each session if they wanted a support person to be there and all said they did. Surprisingly a person who lived independently and had strong communication skills also wanted a support person to be there during the interview. The length of time of interview varied and depended on the communication ability of the PWID. Not all PWIDs answered all the questions, but most answered nearly all. One person refused to be interviewed.

One person had had recent success with controlling their diabetes with exercise and diet and finally did not want to participate as a person with diabetes.

The Ethics Committee of the University of Queensland granted ethics approval for the project.

CONTENT

We consulted a speech pathologist before finalising the wording of the interview. It had a semi-structured form. For ease of expression for PWIDs, we asked people open-ended questions about the challenges of living with both a chronic disease and a disability. A small number of answers were nonsensical and we removed them from the data. We asked support staff and family members questions in the same format to maintain the comparability of the two groups.

The topics discussed were around the lifestyle management of diabetes, learning about diabetes, skills management of diabetes and diet management related to diabetes. We asked for any additional information that people might have at the end of each topic, to cover subjects we may have missed.

DATA MANAGEMENT

We recorded (with the permission of the participants) all the interviews on tape and in written form and we subsequently transcribed them. We then had taped records and written records to maximise efficiency. We transcribed the tapes and crosschecked them against the written records. We therefore used more than one method of recording data, known as triangulation. We then entered the interviews into a database with Access software, with non-identifying codes. We recorded whether each interview was from a PWID, family member, support worker or other professional.

RESULTS

Table 1: Sample Comments from Focus Group Discussions

ISSUES	COMMENTS FROM PEOPLE WITH INTELLECTUAL DISABILITY	COMMENTS FROM FAMILIES AND SUPPORT STAFF
<i>Barriers</i>	<ul style="list-style-type: none">• “Can’t go out”• “Makes you very slow, lethargic, no energy”• “Can’t have what I want when I go out”	<ul style="list-style-type: none">• “Difficult with change(s) of carers”• “Too much of the change especially people with autism, will freak them out and send them backwards not forwards”
<i>Learning Management</i>	<ul style="list-style-type: none">• “Don’t know reading”• “Person showed me all the steps in taking blood sugar”	<ul style="list-style-type: none">• “There are no ID workers working in diabetes and (no) information specifically made”• “Sometimes I just don’t fully understand the diet”

**Skills
Management**

- “(I) Do finger pricking but it does hurt”
- “Need help with readings, and what foods to eat”
- “An ability to understand what and why you do things”
- “I find managing diabetes is not cut and dry and what suits one person doesn’t suit another”

**What Works
Well**

- “I do it all myself”
- “It is easy”
- “It is about sharing the experience and knowledge with other workers”

**Diet
Management**

- “(I) Can’t eat lollies and can’t eat sweet foods”
- “I can’t eat greasy stuff and I can’t eat Chinese all the time and pizza”
- “Carers get meals for me”
- “Same thing for lunch and breakfast”
- “I ask them what I can have”
- “You would give them a choice”.
- “Diet really is an issue”
- “...Eating lots of salad which were a definite dislike”
- “I like her to have fresh fruit and vegetables but she won’t wear her teeth and there is nothing we can do.”

- “Plenty of exercise”
- “I can’t exercise because”
- “They need to know exercise”

- | | | |
|-----------------|---|---|
| Exercise | of my hip” | |
| | <ul style="list-style-type: none"> • “1 hour everyday, have breakfast and 1 hour walk” | |
| Feelings | <ul style="list-style-type: none"> • “I wish I didn’t have it” • “Nothing is easy” • “I hate those feelings” | <ul style="list-style-type: none"> • “It was just such an overwhelming scary thing” • “How am I going to cope with my shift tonight?” |

The themes were extracted from the data from each of the open-ended questions by two independent researchers and the results were compared. All differences were resolved by discussion. The main findings were:

From PEOPLE WITH INTELLECTUAL DISABILITY (n=9)

See table 1.

- **Barriers to management of diabetes.**

PWIDs expressed their perceptions of the barriers to the management or living easily with diabetes as feelings. Nearly all (12/13) answers were about negative feelings in relation to diabetes.

“Stops you doing things”

“I think it’s a bit of a bummer but I have it, so I just have to live with it.....”

“Rules your life”

- **Learning about diabetes**

Most PWIDs spoke about practical issues when asked what they knew about diabetes. One person asked what it (diabetes) was. Frequently people spoke of what they could and could not do.

- **Skills**

People with disability were proud of the skills they had acquired in the care of their disease but these skills were limited in the context of the amount of care needed.

“Change the needle on the pen”
“How to inject myself and all that”
“I do it all myself”

Half of the people said they could assist in their finger pricking procedures. People spoke of what they could and could not eat (some people giving long lists). They described what steps in taking blood glucose levels they could do themselves.

- **What works well**

When asked about the easy things about having diabetes, 6/9 answered and 5/6 of the answers were negative.

“Nothing is easy”
“Can’t get off diabetes. No, have it all the time”.

There was acknowledgement of dependence on families and support staff. One person had clear ideas about what he/she felt their support staff needed to know:

“How to look after me
How to cook good food
How to give me a needle.”

- **Exercise**

Half the people answered the question about exercise, one being a support worker answering for them. All the comments about exercise were positive except one.

“Nearly everyday go walking up to the shopping centre”

“I can’t exercise because of my hips”

- **Diet**

Diet was a more spontaneously talked-about issue than exercise. It is a source of worry, dependence, and conflict but also a subject where some people do make educated choices.

“Lots of things you want but can’t have – no chocolate, Easter eggs, beer or cake.”

“Can’t eat lollies and can’t eat sweet food”

In summary, the PWID needs the family member or support worker to have knowledge and expertise about diabetes. Families and support staff are expected to know about insulin injections and take a lot of the responsibility for exercise and diet. These family members and support staff are also importantly expected to step in and know what they are doing when the person feels ill.

From FAMILIES, SUPPORT STAFF and other PROFESSIONALS (N=58):

See table 1.

- **Barriers**

Families and support staff felt strongly that the biggest barriers to good care were to do with the limited cognitive ability of the people they cared for (46%). Because of this barrier, families and support staff felt PWIDs had difficulty comprehending information and could not cope with difficult words, language or concepts. They reported also that PWIDs forget information easily. They said that this makes it difficult for families and support staff to explain diabetes to them.

However, they maintained that PWIDs could and should be taught in language suitable for them, with material at their standard of comprehension. Support staff felt that a package that was visual, had a range of communication styles, large letters and was activity based with practical demonstrations for day-to-day care should be prepared for their clients.

- **Learning**

Families and support staff said that the lack of staff training was the next most commonly mentioned barrier to good support (21%). Only about half said

professionals in diabetes had taught them about diabetes care (46%). More than half said that they learned informally “on the job” or had no training at all (54%). One support worker expressed the perception of the lack of adequate knowledge felt by many of them as:

“It (training) is very important and relevant to my position as I am the one who takes them off to specialists and things and I am most probably the least person that knows about diabetes and I sit down and go “mmmmmmmmmm.” But I am supposed to be the person who covers these appointments and I don’t know enough”

Staff said that they needed more than their current knowledge. They wanted practical, easy to read information that was basic. They said it should have lots of diagrams and pictures. They said that they should have access to a resource that could answer their questions and they should also have access to a communication book.

- **Skills needed for management of diabetes**

Families and support staff said that skills in monitoring and observation of PWIDs are the most important skills needed for the management of people with intellectual disability and diabetes. Secondly, skills in taking blood sugar levels and skills in teaching PWIDs to self-manage were also important.

“Observation skills – looking for signs especially if non-verbal. Learn about wrong dosage/wrong foods.”

- **What works well**

For suggestions for “what works well” from families and support staff, there was a range of responses. In order of frequency the most common were prompts and supporting PWID (20%), diet management (16%) and management plans (12%).

- **Exercise in diabetes care**

Exercise is a major issue in diabetes care. In contrast with diet management, there is good evidence of effectiveness of exercise in the care of people with diabetes²⁶⁻²⁸. When families and support staff were asked how exercise was managed, most said

that PWIDs do have some form of exercise – most commonly by walking, then swimming then bowling.

“Just gets out and walks on his own”

Some families and support staff said it was just too difficult for some people with intellectual disability. The most common reason given was the lack of motivation because the person just didn’t like it.

“Actually she just likes to sit in front of the TV”

Other co-morbidities besides diabetes often made exercising too hard, according to some families and support staff. The lack of support, which is often needed to be able to do exercise in this population, was also mentioned as a barrier to getting exercise.

- **Diet in diabetes management**

Diet was a major preoccupation of many families and support staff. A large amount of data from the discussions relates to diet. Surprisingly, they also considered it a part of management that strongly “worked well”. However, many also said they were confused about this topic. They commonly said they need more information about diet and nutrition.

“Confused with healthy living / low fat diets”

- **Emotions**

Underlying the themes above there was a common sub theme of the emotions of fear and insecurity that crossed all topics. Sometimes feelings of being overwhelmed were expressed.

“Initially we were a bit frightened too because we could have been responsible for him going into a coma”

“It was just such an overwhelming scary thing”

“How am I going to cope with my shift tonight?”

CONCLUSION

The key findings from this study are that PWIDs have negative views about almost all aspects of living with diabetes. For support staff and families, their knowledge about diabetes is inadequate so they have doubts about their ability to support people. In fact, there is an alarming amount of confusion and anxiety in this group.

“An ability to remain calm (is needed). (To) be supportive because it can be frightening. Staff have found the person on the floor.”

Families and support staff saw the skills of monitoring and observation as being more important than the more practical skill of knowing how to take blood sugar levels. If this is true, it implies that families and support staff need a depth of knowledge about the person to be able to pick up on changes and they also need time during a shift to watch the person. In paid caring circumstances this is not always possible. Long-term working relationships are not the rule²⁹. It may be necessary to have increased staff numbers and skills to enable basic monitoring and observation.

The anxiety expressed by support staff may be partly due to the high turnover rate of staff in the disability sector. This exacerbates the state of inadequately trained staff. However, there is a duty of care to ensure that “You must take reasonable care to avoid acts or omissions which you can reasonably foresee would be likely to injure your neighbour”³⁰. This principle is firmly embedded in the law of negligence of most common law countries³¹. Further, “They (authorities) must do it (care) by the staff which they employ, and, if their staff are negligent in giving the treatment, they are just as liable for that negligence as is anyone else who employs others to do his duty for him”³².

To optimise diabetic management and to avoid legal ramifications, increased education for PWIDs, families and support staff is needed. Better resources should also be available. People with disability need courses designed for them and given to them by people trained in communicating with this population. Families and support staff need to receive training from experts familiar with the sector and its unique

characteristics. Current courses available do not seem to be effective, according to this survey.

This work, interviewing people with disability and their families and support staff about this disease has not been done before. Unfortunately it exposes serious inadequacies of training and management. It may not be appropriate to generalise the findings of this paper, as other places may approach the issues presented in different ways. In any situation, we consider that that support should be knowledgeable and competent at all times, and particularly so with a potentially dangerous condition such as diabetes.

For the person with a disability, further complications brought on by poorly controlled diabetes to an already complex life are potentially very harmful. This is particularly so for them as a people who are already marginalised and often of sub-optimal health. In the future more people with disability are going to have to cope with the burden of this disease. As our contribution to dealing with this dilemma, and based on the needs expressed in this project, this centre developed a website that can be found at www.sph.uq.edu.au/diabetes.

Diabetes mellitus has the advantage of being a clearly defined condition with well-established guidelines for management. This is unlike many of the other morbidities experienced by PWIDs, such as mental disorders. However, in spite of the clarity and knowledge about diabetes, those who provide support feel inadequate, anxious and untrained. As a marker of the management of co-morbidity in people with intellectual disability, our study in diabetes care strongly suggests there remain many areas of potential improvement that need to be addressed.

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