

Original Article

Perspectives on clinic attendance, medication and foot-care among people with diabetes in the Torres Strait Islands and Northern Peninsula Area

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Abstract

Objective: To achieve a better understanding of the perspectives and needs of Indigenous people with diabetes in the Torres Strait and to identify ways to promote successful self-management of diabetes.

Design: Descriptive study collecting qualitative data in focus groups and in-depth interviews. Analysis of three key areas of diabetes self-care, namely attending appointments at the clinic, monitoring blood glucose levels and taking medication and foot-care.

Setting: Informal settings in remote communities of the Torres Strait and Northern Peninsula Area of Far North Queensland.

Subjects: Sixty-seven Torres Strait Islanders (26 men and 41 women) with diabetes from eight Torres Strait and Northern Peninsula Area communities.

Main outcome measures: A better understanding of the views, enabling factors and barriers that people experience when managing their diabetes in remote Torres Strait communities.

Results: Participants who expressed satisfaction with clinical-initiated sessions when called highlighted positive relationships and encouraging feedback from doctors. People's attitudes and practices related to oral and injectable treatments varied widely, possibly linked to levels of understanding. Widespread knowledge of foot-care and fear of amputation in an environment highly

conducive to foot sores and infection was evident. Generally, participants wanted more education and personal support in all areas of diabetes care. Service providers in health and other sectors need to place more emphasis on supporting self-management of diabetes within the family and community environment.

KEY WORDS: diabetic complications, health services, Indigenous, qualitative.

Introduction

The number of people with type 2 diabetes is increasing globally.^{1,2} Indigenous populations in developed countries often experience higher rates of diabetes than the general population.³ In Australia, people of the Torres Strait Islands have an extremely high prevalence of diabetes of 51% among women and 25% among men over 35 years.⁴ Complications are frequent and occur at young ages.^{5–8}

Of particular potential interest to addressing this issue is the local strategy, *Meriba Zageh for Diabetes*, implemented in 1996 and reviewed in 2000.^{9–12} This revealed significant improvements in early detection and clinical management but little progress in helping people take everyday self-care action at home.^{9,10,12}

Successful management of diabetes at home requires a close partnership between client, family, health service and community.^{13–15} Often the client has the least chance to voice his/her views and needs in achieving good self-care.¹⁵ The aim of this project was to gain and share a better understanding of the perspectives, strengths and needs of people with diabetes in the region so that the community, health service and clients are able to implement positive changes that directly support clients to achieve maximum self-care.

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What is already known on this subject: It is possible to live a long and healthy life with type 2 diabetes. Significant lifestyle changes are required to achieve this, which include a number of social, emotional and lifestyle adaptations. Torres Strait Islanders with diabetes suffer a much higher rate of complications and early death than non-Indigenous Australians, indicating that services are not effectively helping people to make these adaptations.

What this study adds: This study provides a better understanding of the views, enabling factors and barriers experienced by people with type 2 diabetes living in the Torres Strait, especially in relation to regular appointments, use of medication and professional services for foot-care. Also provided in the study is insight into the needs and struggles that clients with type 2 diabetes face, in order to achieve a healthier life and information for the clinician, health workers, families and the community about what is required to assist people with diabetes to make changes in the way they manage diabetes.

Methods

The research team consisted of two Torres Strait Islander health workers supervised and supported by senior researchers in Indigenous and public health. Both workers had extensive experience working with people with diabetes and shared cultural background and dialect with the participants. Ethical clearance was granted by Cairns Base Hospital in 2001. Health workers at each site identified and helped recruit clients from the Diabetes Register for the study using information sheets and consent forms.

Sampling

Two small communities in the Torres Strait and Northern Peninsula Area District were selected for convenience and a further six were randomly selected from the total of 21. Up to 20 clients from each community were invited to participate in focus groups (held separately for men and women) and/or in-depth interviews. Qualitative data collection tools were developed using a matrix involving key behaviour change aspects of key self-care practices. Data were recorded, transcribed and coded for thematic analysis.

Results

Characteristics of the participants

One hundred and fifty-six people named on the diabetes registers in participating communities were approached to participate in the focus groups. Of these, 133 were able to be contacted and issued an invitation; and most expressed willingness to be involved. Of the 133, 67 (50%) took part in 11 focus groups and 30 in individual interviews. The most common reason for not participating was time conflicts with work, church and family duties. Twenty-six men and 41 women participated with an age distribution shown in Figure 1.

Results from the focus groups and interviews are presented below. This paper will highlight themes and com-

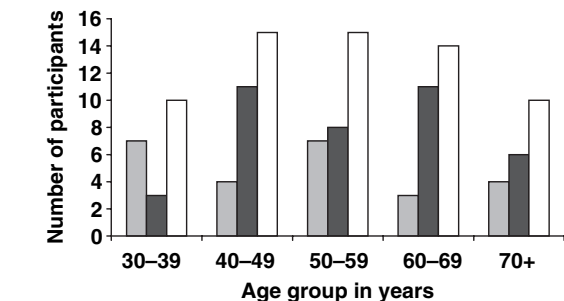


FIGURE 1: Age and sex distribution of participants. (□) men; (■) women; (□) total.)

ments related to three key dimensions of diabetes self-management, namely regular clinic attendance, following clinical instructions and taking care of feet.

Key area 1: going to the clinic regularly

Enabling factors The first key area covered issues surrounding going to the clinic regularly if something is wrong and keeping appointments when recalled. Most participants knew the importance of going to the clinic if something was wrong. When asked, ‘If you have problems with your diabetes at home what do you do?’ typical responses included ‘Go to the Health Centre and see Doctor’, ‘If I feel sleepy or dizzy, I work in the hospital, so I tell sister or doctor’, ‘my partner mentioned to me to go and have a check up because I was sleeping too much’. Some seek reassurance, for example, ‘Yes, if I worry then I must go and check out my blood sugar, when I check out my blood sugar then it’s alright’ and ‘When that feeling comes (like I’m going to drop/faint) then I must ring up the Health Centre and ask them to check my blood sugar and my blood pressure’.

Most participants were also aware of the importance of keeping appointments when called, as one said, 'We know that we need to get check up so we don't get upset' and another said simply, 'No problems with appointments. I go'. People are motivated to attend by learning and positive feedback, for example 'I look forward to get the appointment from the specialist. It's good to find out about my results and ask questions. It's a good feeling when everything is okay' and 'I ask the questions and they tell me the answers and I get a good feeling'. Others worry that something will be wrong.

Some participants' comments revealed assumptions about others being responsible for their diabetes care, for example one said, 'The responsibility is for the health workers. They send us the appointments, but they should remind us and do it cause they specialise in that area'. Some feel annoyed with appointment letters, as one explained, 'Well it's like this, Oh not again, then you think again and you think well they're just doing their work it's best for you'. Some described nonattendance as a personal struggle, for example 'I have a problem with that, it's just me. I need to tell myself to do it and then I will go when I feel like it'.

Barriers identified by people as preventing them from attending the clinic regularly included work-based constraints and, among the elderly, transport problems. Some councils have adopted helpful health promoting policies for staff, as one man stated, 'Well, there is a policy in place and Council lets us go according to the appointment time. If I go to the clinic and there is someone else there, I will go back to work, so that I don't lose my pay'. Frequent references were made to long waiting time, leading to missed appointments.

Key area 2: following clinical instructions

The second key area focused on issues surrounding taking medication regularly and monitoring blood sugar levels. Most participants knew the consequences of missing tablets. A female participant said, 'I worry when I run out of tablets, I understand when my sugar plays up. I know it maybe its stress etc., so I try to get the sugar down'. Another said, 'Yes. Sometimes I forget to take tablets and when I forget I go home and have something to eat and then take my tablet'. Another said, 'When I leave the tablets my sugar goes up or goes down, I know that 10 down is okay and 10 up is no good'. Sometimes clients run out of tablets and wait to get more. One woman described how not taking tablets helped her deny her illness, 'I feel that I make myself feel that I am not a diabetic ... when my tablets run out it takes me a long time before I will go and get my tablets'.

Knowledge and practice with insulin among some participants seemed trouble-free. For example, a woman

said, 'I used to give myself insulin for 9 months when I was pregnant, I had to go inside hospital and they showed me there about the insulin. I never worried about sugar'. Another explained, 'I follow instructions. I'm not on tablets I got my syringe and use insulin. It does me very good. When I was on tablets my sugar was high. Insulin is good, I go strictly on my diet'.

While most go to the health centre, some participants had a glucometer at home, enabling them to self-monitor their glucose levels with little trouble. Comments were made such as 'I have my own machine so I monitor my blood sugar at home. The others come and do it at the health centre' and 'I prick my finger and then bring my paper with my recordings in to show doctor my results'.

Although most participants understood the importance of taking medication regularly, most had little knowledge about why, as one said, 'They don't explain what it's for. Sometimes the doctor just checks the charts for obs and then sends them away'. A desire for greater understanding was common, '... the medication, how it works when you take it. When you go to the hospital they change your medication ... they don't sit with you and explain it to you'.

The consequences of not understanding medications can be serious, as one explained, 'I'm not keeping control of my sugar levels ... I came off insulin but it was a mistake. I had to stay in hospital until I came good. Now I need to take more insulin units. Doctor didn't tell me I just went off it myself'.

Several women described connections between emotions and medication likely to influence compliance, for example 'For me if I'm happy with the medication then it will work for me. If I'm not happy and they are giving it to me it won't work on me' and 'I don't like tablets because the tablets make me feel lazy and sleepy and I can't move around at my house'.

Spiritual faith helps many people cope with diabetes management, as two women explained, 'Now I know if we have prayer, exercise and tablets it's good to keep us going' and 'I trust the word of the untap man (God), that's where I put my faith. I don't stop praying, take my medication and do exercise'.

Some participants identified lack of family support as a problem, as shown by comments such as, 'We need more time and we need the family to support us' and 'How do we tell them? They should be there when we see the doctor'.

Most participants indicated that doing things for themselves by taking medication, regularly monitoring blood glucose levels, going for walks and trying to eat well led to important positive feelings, 'Once you overcome the high sugars, you feel proud of yourself. You go through the different stages when your sugar is high or low it affects your feelings'.

Key area 3: taking care of feet

Losing a toe or foot is a common and highly visible complication of diabetes in the Torres Strait. Most participants had a good understanding of how to take care of their feet, expressing this in various ways, 'Wear shoes, cut toenails, make sure you wear shoes all the time', 'Wear proper foot wear, when you have a shower make sure to check under your foot for cuts or anything like that, have your nails trimmed regularly. Rub moisturising cream on your foot to make sure there are no rashes or dry skin', 'Doctor said to wear shoes, covered footwear for bumps. Be very careful when you go out and clean the yard' and 'Yes, when you rub the cream under your feet and you wear your shoes the split under your feet comes good again'. A few were unaware of these practices and found the focus groups informative.

Nearly all participants said they wear shoes, clearly recognised the importance of taking care of feet and were aware of the dangers that diabetes adds to foot sores. The connection and fear of amputation is very strong, as explained in these two quotes, 'It is important to check your feet because if there is no pulse they may have to amputate. Sometimes I check if I've got any feeling and I stand on top of a sharp object for feelings' and 'Well, my toenails, I cut them. The corns underneath I do myself. I usually get my grand daughter to check for my foot pulse, if she can't feel it, or if she says that there is no pulse then I check it myself. I panic if she can't feel it so then I check it myself'. Some emphasised the need to seek medical advice, as one man said 'Yes, any sore or cut you get, you should go straight to the Health Centre for dressing. It is very important', and the price paid for not being careful, 'Yes, it is the most important thing, your legs, your feet. If you have half a leg you feel useless'.

Men often described protecting their feet on the reef, explaining, 'I have no problems with my feet. I used to walk about barefoot but now I wear shoes all the time or sandal or thongs' and '... when you go out on the reef or fishing we must wear thongs or some sort of protection. If you get a sore then you must treat it straight away, don't let it get infected'.

Annual podiatrist visits to check client's feet are valued, but not considered sufficient to provide regular advice and care. For example, one woman said, 'With ingrown toenails you have to be careful when you cut your nails in case you make a sore. However she should come more often', while another commented, 'When the podiatrist saw me she said, "Who cut you toenails?" I said "I do it myself", and she said, "You shouldn't do it", I said "Well I do it myself because you never come to see us". That's why I lost my toe. You got to come and see us more often'.

While participants had different attitudes about foot-care, the underlying motivation was fear of amputation. A young woman said, 'I check my toes every time. Aunty ... her toe it was numb as she had a stone in her toe. She called someone to come and have a look at her toe and they found stone in her toe. I always remember this, so I make sure that I always check my feet and make sure that it is okay. I use a scrubbing brush to scrub my feet. Only toenails too long'. Another woman in her fifties said, 'I take care of my heart and my feet. I lost a toe, I had a bit taken out. I learnt the hard way'. Spiritual faith helps many people deal with fear of amputation. An older woman said, 'I had cracked feet since 1993. I used prayer and my cracked feet came okay from prayer. This is my inner secret'.

One common belief in the Torres Strait is that amputation is caused by sugar deposited in the limb. As one explained, 'that's where most of the sugar goes, say if you are taking too much sugar, that's where it builds up down there, from bit of weight. That's the first place they will start cutting off'. He further explained, 'Well you know that's what they do first, where they cut off the leg. The sugar settles in your foot'.

Most barriers preventing good foot-care relate to isolation and remoteness, having only intermittent access to doctors/podiatrists and no access to good shoes. Physical immobility is also a problem that requires family help, 'If I get a splinter, especially on this leg, I can't bend it all the way up so I get them to look at it. They will have a look and take it out.'

Discussion

Achieving good self-care for diabetes is not easy, even in the best of situations.^{13,14} For type 2 diabetes, this usually involves a number of behavioural changes that impact on almost every aspect of a person's life. Such changes are particularly difficult for people living in remote areas and who lack resources and access to a wide range of choices. Educational and psychosocial interventions have a positive impact on the management of diabetes.^{16,17}

As diabetes needs to be regularly reviewed, effective recall and reminder systems play a critical part in the management of diabetes. Different views were expressed about visiting the clinic regularly, keeping appointments and doctor's recalls. Most clients reported that they went quickly when they were worried; most said they attended specialist appointments. Others described problems with time, remembering or reliance on health workers to call them. Long waiting time is an issue as clients return home or go to work without seeing the specialist.

Many participants did not have glucometers and could not monitor blood sugar levels at home. Those

with machines expressed no difficulty in using them, clear understanding of the link between eating foods and glucose levels and more confidence in communicating their self-management experience with the doctor.

Most people said they can follow doctors' instructions in taking medication regularly but few understood how medications work. Clearer information about diabetes medications including insulin plus stories of successful use in the Torres Strait is needed to prevent unwise decisions about stopping medication and reduce fear of insulin.

Many diabetics experience nerve tissue damage and poor blood circulation that results in the need to pay particular attention to their feet.⁸ As Levin states, 'The loss of a limb limits daily activity and leisure activities ... frequently leads to early retirement and loss of income. In addition, "friends" often desert a person who has a disability'.¹⁸ Good understanding of foot-care and strong fear of amputation were widespread among all participants, however, foot problems were clearly visible. One had below-the-knee amputation, two had toes removed and four had foot sores needing daily dressings.

Podiatrists are an integral part of a multidisciplinary diabetes care team aiming to reduce complications associated with diabetes.^{8,19} Most participants saw the podiatrist yearly but wanted more regular visits. The humid tropical climate is ideal for rapid bacterial multiplication; a scratch on a diabetic foot may rapidly progress from bacterial infection, ulceration to amputation if not immediately treated. Suitable, affordable footwear is also needed at local shops.

The study group included people who were more successful at managing their diabetes at home as well as some who were not so successful, but the latter are probably under-represented. While women outnumbered men among the participants, this is expected because of the higher prevalence of diabetes among women. Future work should focus on gaining a better understanding of the perspective of people having trouble accepting their illness and making lifestyle changes such as improving diet, increasing physical activity, attending clinic appointments and taking their medication.

The study also revealed that there was a need to have support groups in place, which should include family and friends as well as people with diabetes. The group can share in activities like walking or cooking; but mainly to 'come together and talk about things'; 'things' referring to difficulties they are experiencing in achieving good self-care. Strengthening the voices of people with diabetes may be the key to both self-management and, ultimately, prevention of diabetes in these close-knit communities.

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