The impact of living with type 2 diabetes: a descriptive qualitative case study with four Pacific participants

Darlene PUPI,¹ Trudy SULLIVAN,² Kirsten COPPELL³*

ABSTRACT

Introduction: Diabetes is a common among Pacific peoples. The personal cost of diabetes is substantial with the indirect costs shown to outweigh the direct costs in some instances. The aim of this case study was to identify and describe the personal cost to four Pacific people living with type 2 diabetes in New Zealand.

Methods: Two Pacific men and two Pacific women with type 2 diabetes were recruited with the assistance of the Pacific Island Centre and the Pacific Research Student Support Unit, University of Otago, Dunedin, New Zealand. The participants were interviewed (three in Samoan and one in English) using an open question approach. Appropriate cultural protocols were observed, and interviews were audio-recorded and transcribed. Samoan interviews were translated into English. A thematic analysis was undertaken using an inductive approach.

Findings: Participants’ ages ranged from mid-30s to 75 years. The two retired participants had difficulty paying their prescription fees and three participants considered healthy food expensive. Other costs included time off work and family members moving towns to take care of participants and their diabetes. Pacific community members provided time, gifts and money at times when participants were less well. At the same time, participants considered they had a role in educating their community about diabetes prevention. A diagnosis of diabetes triggered healthful lifestyle changes for one participant.

Conclusions: The personal cost associated with diabetes is broad and complex, with particular implications for roles and responsibilities among Pacific communities.

Key words: Pacific people, Type 2 diabetes, Cost of illness, Indirect costs

INTRODUCTION

Diabetes mellitus is a common chronic illness. In New Zealand (NZ) the prevalence of diabetes among those aged 15 years and over is 7%, with the highest prevalence rate in Pacific people (15.4%) compared with Māori (9.8%) and NZ European (6.1%).¹ The average age at diagnosis is younger among Pacific people (49 years) and Māori (43 years) than in NZ Europeans (55 years).² adolescents and young adults are increasingly diagnosed with type 2 diabetes (T2DM), particularly among Pacific.³

¹Medical Student, Medical student, University of Otago, Dunedin, NZ
²Health Economist, Department of Preventive and Social Medicine, University of Otago, Dunedin, NZ
³Senior Research Fellow, Department of Medicine, University of Otago, Dunedin, New Zealand. kirsten.coppell@otago.ac.nz

Received: 21.05.2018; Published: 30.09.2018


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The economic cost of diabetes is substantial.\textsuperscript{4, 5} The direct costs of managing and treating the disease and its associated complications, as well as the indirect costs such as productivity loss and intangible costs such as the psychological cost of having diabetes, all contribute to the cost of having diabetes. A large part of the direct cost of diabetes is due to the treatment of complications, including diabetic eye disease, cardiovascular disease, diabetic foot disease and lower limb amputation, and diabetic nephropathy, which can progress to end stage renal failure requiring costly dialysis.\textsuperscript{6}

It is now recognised that the indirect cost of diabetes can outweigh the direct costs. In Italy the estimated total economic cost of diabetes in 2012 was €20.3 billion, with 54\% associated with indirect costs, and 46\% associated with direct costs.\textsuperscript{7} Similarly, a study in the United States (US) estimated the direct costs of diabetes to be US$44 billion per year, and indirect costs US$54 billion.\textsuperscript{8}

Few studies have examined the economic impact of diabetes in Pacific populations, but the available information suggests diabetes is costly in these communities. An estimated 20\% of the Government’s health budget in the Solomon Islands and Nauru is spent on health care relating to diabetes.\textsuperscript{9} At an individual level, the main costs associated with diabetes management in Vanuatu are over-the-counter-medications, transport to hospital facilities and the extra cost of recommended foods as part of diabetes management.\textsuperscript{10}

In NZ, Pacific peoples make up almost 8\% of the population, and while they have disproportionately high rates of diabetes, there is no research that looks at the personal cost of diabetes in this group. This study sought to explore and provide an understanding of the personal cost to Pacific peoples with T2DM by identifying and describing the costs faced by four Pacific people with T2DM living in NZ.

METHODS

This qualitative case study was conducted in Dunedin, NZ, between December 2016 and February 2017. The research interviewer (DP) was a Samoan university student living in Dunedin. The University of Otago Human Ethics Committee approved this study (D16/377).

Participant Recruitment

Four Pacific people with T2DM resident in Dunedin were recruited with the help of the Pacific Island Centre and the Pacific Research Student Support Unit, University of Otago, Dunedin. Potential study participants were given the study information sheet and asked to provide their contact phone number if they were interested in participating in the study. Their names and contact details were forwarded to DP who arranged a time and place for an interview. Participants were given a choice as to where they were interviewed, (their home, a café, or the University), and whether the interviews were conducted in Samoan or English. They were invited to ask questions about the study and written consent was obtained.

Data collection

All participants were interviewed at the University, three in Samoan and one in English. An open-ended question approach was used and appropriate cultural protocols were observed during the interview process. The interviews, with consent, were audio-recorded. The length of each of interview ranged from 30-60 minutes and after each interview, the participant was offered a $50 grocery voucher. DP translated and transcribed the three Samoan audio-recordings and transcribed the English audio-recordings.

Data Analyses

All three investigators read the transcripts multiple times. A demographic description including gender, age, occupation, and living situation, including who lives with them, was summarised for each participant. A thematic analysis was undertaken using an inductive approach.\textsuperscript{11} Text was coded and categorised manually. Codes and categories were discussed, and main themes highlighted.

RESULTS

The demographic characteristics and duration of diagnosed diabetes for each participant are presented in Table 1. Each participant had a unique role in their household and in their community. The context of having diabetes was different for each participant. Diabetic retinopathy was the only complication reported.
Table 1. Demographic characteristics of participants

<table>
<thead>
<tr>
<th></th>
<th>Participant 1</th>
<th>Participant 2</th>
<th>Participant 3</th>
<th>Participant 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Female</td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>Age (years)</td>
<td>65</td>
<td>75</td>
<td>Mid 30s</td>
<td>59</td>
</tr>
<tr>
<td>Pacific group</td>
<td>Samoan</td>
<td>Samoan</td>
<td>Samoan</td>
<td>Fijian</td>
</tr>
<tr>
<td>Interview language</td>
<td>Samoan</td>
<td>Samoan</td>
<td>Samoan</td>
<td>English</td>
</tr>
<tr>
<td>Duration of diagnosed diabetes</td>
<td>About 2 years (unable to recall exactly)</td>
<td>Years (unable to recall exactly)</td>
<td>One year</td>
<td>About five years</td>
</tr>
<tr>
<td>Occupation</td>
<td>Retired</td>
<td>Retired</td>
<td>Administrator</td>
<td>Caterer</td>
</tr>
</tbody>
</table>

**Personal costs and ‘benefits’ for participants**

Both costs and ‘benefits’ (that is, positive aspects) following a diagnosis of diabetes were identified. Costs included diabetes medicines, general practice visits, extra costs for healthy food, costs to the family, costs to the community, and productivity loss, while benefits following a diagnosis of diabetes included adoption of a better lifestyle and assuming a responsibility to help others in the community better manage their diabetes or avoid getting diabetes.

**Medication costs**: All participants were taking Metformin for blood glucose control. Unlike the younger working-age participants, the two retirees could not always afford the prescription fee and often negotiated with their pharmacists to make the payment at a later date.

**General Practitioner visits**: A regular cost for the participants were general practitioner (GP) consultations for a diabetes review and a repeat Metformin prescription every three months. GP visits were six-monthly for one participant, whose blood glucose was well-controlled. Attending GP visits was easier for retired participants as they had more time, compared with those who were working.

**Extra food costs**: All participants considered eating a healthy diet was more expensive than an unhealthy diet, which limited food choice at times, causing additional stress.

“There’s a lot more cost to eating healthy.” [Participant 3]

“Sometimes, whatever is left in the cupboard is all we’ve got…so we just eat rice and bread…” [Participant 1]

The cost of food for other household members was also a consideration, particularly if they did not want to eat different meals.

“You know it’s not just you, it’s a family of four, so you have to cater for all those other people as well.” [Participant 3]

**Costs to the family**

The cost of diabetes to the family was wide-reaching. One participant took early retirement because of diabetes (and other health issues). This created financial stress as they were the sole provider for their family. As a result, one child in the household had to take a year off school to undertake paid employment. The niece of another participant moved from elsewhere in NZ to live closer and help with household chores.

For the two retirees, their children or another family member usually took them to doctors’ and hospital appointments. These family members took time off work to do this, and to care for them when they were sick. Sometimes children travelled or wanted to travel from afar to help.

“My children were so worried… My oldest boy was going to come down…I told him ‘no don’t come’, cause it’s really far, 26 hours flight, and they have young children with them.” [Participant 1]
Cost to the community

The impact of participants being unwell extended beyond the immediate family to affecting the local Pacific community. Commonly, if participants were hospitalised or too sick to go to church, people from their church, including the pastor, visited, bringing food. These times of incapacitating sickness limited participants’ ability to fulfil their specific roles in the Pacific community and the church, for example, Sunday school teacher, deacon, leader of the youth group, or elder of the community which involves making decisions for the community.

Intangible costs

A common feeling shared amongst the participants was the shock and disappointment following a diagnosis of diabetes, particularly if they had been asymptomatic. They did not understand why they had developed diabetes.

“It saddens me that I have it...and now I have to suffer because of this... I don’t know the reason I have it.” [Participant 1]

Diabetes negatively impacted on the quality of life for most participants. The participants who worked found diabetes was just another burden placed upon them that they had to fit into their busy work and family schedules. Diabetes had triggered early retirement for one participant, and had prevented another from doing things he used to love, like cooking for the church and family, fishing, and playing rugby.

Attendance at ‘toona’i’ or ‘church lunch’, which is held at least once a month, was stressful because of the expectation for everyone to eat. Participants found it difficult to maintain a healthy diet, when unhealthy food was on offer.

Better diet

One participant explained that he quit smoking and alcohol after being diagnosed with diabetes, which saved money. He used this money to buy healthy foods.

“...the biggest budget I had was alcohol, the biggest money spent was on alcohol, and cigarettes ... all of that is gone, so that’s a lot of money, compared to the price that I have to pay in terms of food ...no I didn’t spend more money, I actually spent less...” [Participant 4]

Family and community

A community elder, who said he was not ashamed of having diabetes, believed that Pacific peoples need to know that diabetes is a huge health problem. Since being diagnosed with diabetes, he has tried to educate and encourage family and community members to lead a healthy lifestyle to prevent diabetes, by sharing his story with them. He has also tried to influence what is eaten by people with diabetes when they have community feasts.

Another participant described that one benefit of being part of a close community was the feeling of never being alone. Knowing that other people in the church also suffered from diabetes was a comfort.

Future health

One participant considered being diagnosed with diabetes was more of a blessing rather than a curse. The diagnosis was a wake-up call, which triggered a lifestyle change.

“When I found that I had diabetes it’s a wake-up call, you know, do something with your lifestyle, so I completely turned it around and said no more alcohol, because that’s the cause of all the high sugar, you know .... And then ever since I’ve been really happy with you know, with what’s happened since then...” [Participant 4]

DISCUSSION

This case study sought to identify and describe the personal cost of diabetes among four Pacific people with T2DM living in NZ. The personal costs identified were medications, GP consultations, and cost associated with healthy food choices and the additional roles and responsibilities that family members and the wider community had to fulfil at times. Although this case study comprised only four people, the personal costs described by participants were similar to those identified by Tin et al (2015) among Pacific people in Nauru and the Solomon Islands.

The direct cost of diabetes is significant, but the indirect costs may be even larger. Diabetes can be a significant burden on the individual and this burden can vary depending on an individual's family circumstances, social situation and background, and can cause significant stress. This study, which explored the impact of diabetes on four Pacific people, allowed us to describe and acknowledge the complexity of the cost of diabetes among Pacific families. It was evident
that the personal cost of diabetes extends beyond the person with diabetes to include the family, as well as the wider Pacific community. When personal costs are taken into account, the economic cost of diabetes is likely to be greater than current estimates of the cost of diabetes.\(^8\)

One unique cost of diabetes amongst Pacific peoples is the cost it places on the family. In Pacific culture, ‘aiga' or family is prioritised above everything, so if one person in a Pacific family is sick, the impact extends to the whole family.\(^12\)\(^,\)\(^13\) Younger family members, as found in this study, often lived with the person with diabetes to help with household chores and keep them company. This commitment sometimes involves moving from another town or country. Moreover, extended family and members of the community find time and money to visit and bring gifts, as a sign of love and care.

In Pacific culture, elders are highly respected, and their needs and wants are prioritised within the Pacific community.\(^14\) Sometimes when immediate family are unable to help, church community members take up the carer role for the sick person, giving money and time which can necessitate taking time off work. This is not an obligation, but rather the nature of the Pacific culture where everyone in the community becomes family (biological or non-biological). These sociocultural practices, which we identified in this study, emphasise the uniqueness and potentially greater economic impact diabetes has among Pacific peoples.

Food is an important part of Pacific culture, and is always present at Pacific gatherings, whether it is a celebration such as a wedding or a funeral, church lunches, or visiting someone.\(^12\)\(^,\)\(^1.\)\(^4\)\(^,\)\(^15\) In the Pacific culture offering food can be a sign of a gift or respect and in Samoa is called ‘faaaloalo'. While it is polite to accept these foods or the ‘faaaloalo', this cultural practice can be a challenge for people with diabetes. In our study, one participant described that when they attended ‘toona’i' or ‘church lunch', it was difficult to maintain a healthy diet when people brought unhealthy food. Despite knowing that a poor diet has an impact on glycaemic control, it was difficult to resist the temptation of unhealthy food, and refusing the ‘faaaloalo' could be considered rude. This difficulty with diabetes management has been previously described as a source of stress for Pacific people with diabetes.\(^12\) In contrast, one participant was able to decline the ‘faaaloalo' at gatherings by explaining that he had diabetes and was not able to eat unhealthy foods. This person was, however, highly motivated to change their lifestyle, and had stopped smoking and drinking alcohol, and had made dietary changes to reduce the risk of diabetes progression and development of complications. It was beyond the aim of this study to determine what factors helped facilitate the adoption of a healthy lifestyle.

People with diabetes are usually aware that they need to eat a healthy diet but it can be costly, particularly when there are other costs associated with having diabetes such as GP consultations and prescription fees.\(^16\) These additional costs can create stress especially when trying to adopt a healthier lifestyle, and particularly within a family setting.\(^12\) This means that people may not always eat and drink recommended foods for diet-related conditions, but will consume what is affordable and available to them.

A limited budget, lack of time and a negative mindset or lack of personal motivation are barriers to implementing a healthy lifestyle.\(^15\) In this study changing one's mindset was considered a barrier because lifestyle changes were difficult to make, and that to implement these changes, the whole family has to agree and follow the changes too. A suggested and previously recommended solution for Pacific people was to involve family members in the treatment and management plan of the person with diabetes.\(^12\) The same concept might also be useful to consider in health promotion – to not only target the person with diabetes but also the family members, as well as the wider Pacific community.

A common, and previously described theme,\(^17\) amongst all four participants was the shock of learning they had diabetes. Two participants did not understand why they had diabetes because they thought they had always eaten healthily. The news of having diabetes did not make sense to them, and initially, they did not change their diet. They later become more aware of their diet, eating more fruits and vegetables, however that was the only change, and they did not necessarily reduce their intake of unhealthy foods. This was similar to findings in a study by Green et al (2007).\(^18\) where people diagnosed with T2DM had positive attitudes and good knowledge to make changes to their lifestyle, however most did not take action in regard to their diet, exercise and weight loss.

\textbf{Strengths and limitations}

A key strength was that the interviewing researcher was Pacific (Samoan). This helped participants to feel more comfortable during the research process, particularly for three participants whose interview was conducted in
Samoan. The implication is that they may have been more willing to share information, thereby providing rich data for analysis. A limitation was that recall of lifestyle changes made following a diagnosis of diabetes was difficult for those participants who had had diabetes for a long time, particularly if these changes have become normalised as part of their lifestyle. This small qualitative case study did not include the quantification of any actual costs. As household and family members were not interviewed, not all personal costs may have been identified. Three of the four participants were Samoan, and the findings may not be generalisable to all Pacific ethnic groups. Indeed, though informative, the findings may not be generalisable to the wider Pacific community given the small number of participants in this case study.

CONCLUSION

The economic cost of diabetes among Pacific is wide-reaching, and has a huge cultural aspect. Among Pacific peoples there appears to be a significant cost to not only the person with diabetes but also family and community members. A diagnosis of diabetes can have a positive outcome, whereby the diagnosis triggers a dramatic lifestyle change, and can lead to individuals being a positive influence on family and the community. More research is needed to better understand and quantify the cost of diabetes among Pacific people, and to tailor diabetes prevention and treatment programmes to reduce the personal and economic cost of living with diabetes.

Acknowledgements

We thank the four participants who took part in this study, and the Pacific Island Centre and the Pacific Research Student Support Unit, University of Otago, Dunedin who helped to facilitate recruitment.

REFERENCES


