

## PERCEPTIONS OF PEOPLE WITH TYPE 2 DIABETES ABOUT SELF-MANAGEMENT AND THE EFFICACY OF COMMUNITY BASED SERVICES

### **Abstract**

Self-management has become a key strategy for managing the health care of people with diabetes. This study explored issues people with type 2 diabetes experienced in their self-management practices and access to regional community based services. Using a qualitative interpretative design data was collected from four participants who were interviewed about their perceptions of facilitators, barriers and issues they encountered in their diabetes care in a regional setting. The findings indicate difficulties participants experienced in gaining access to quality services in regional areas, including long waiting times, difficulties making appointments, and their perception that healthcare professionals fail to acknowledge patients self-management knowledge and practices. Additionally, participants reported food choices affected their family relationships and experience of social stigma. These issues compromised their self-management decisions. The findings indicate a need for health professionals to develop strategies to improve community based services for people with type 2 diabetes and to increase public awareness of the scope of diabetes management.

**KEY WORDS:** type 2 diabetes, consumer, community services, qualitative research.

## INTRODUCTION

Diabetes is a major international health issue (Holman & Lorig 2004; Australian Institute of Health and Welfare [AIHW] 2002) with a dramatic increase in the number of people diagnosed with type 2 diabetes (Dunstan et al. 2002) resulting in significant burden for individuals, their families and the community. Type 2 diabetes is associated with a range of factors that contribute to insulin resistance and subsequent elevation of blood glucose levels (BLGs) (Harmel & Mathur 2004). Type 2 diabetes may be managed through diet and exercise alone, or through both diet and oral hypoglycaemic medications, and/or additionally with insulin injections (WHO 2004). If left untreated, it can lead to serious short and long-term complications.

A diagnosis of diabetes carries its own psychological and social burdens. Self-management is a constant and time consuming task, and requires considerable self-discipline, taking a minimum of two hours a day for a person with stabilised type 2 diabetes, with diet and exercise being the most time consuming aspects of care (Russell, Churl Suh & Safford 2005). Diabetes Self-Management Education (DSME) interventions and programs have proven successful in contributing to people's ability to make decisions about their illness management (Lorig et al., 2001; Steed 2005). A number of studies suggest that healthcare professionals and community service providers can support people with diabetes by providing adequate knowledge and supported self-management education (Bodenheimer et al. 2002; Ah Kit et al. 2003).

Optimal diabetes care includes regular eye examinations, foot care, monitoring of glycaemic control, blood pressure and cholesterol checks, which are essential in minimising and preventing future diabetes related complications (Engelgau et al.

2003). This care is delivered in communities by a range of professionals including general practitioners (GPs), diabetes educators (Knuiman, Welborn & Bartholomew, 1996; Nocon et al. 2004), dieticians, optometrists, district and community nurses (Linekin, 2003), mental health services and diabetes organisations (AIHW 2002; Schmidt 2003). Difficulties can arise if the coordination between services is poor and result in people having problems making appointments and needing to travel to multiple locations (Van Eyk & Baum 2002; Yip et al. 2002).

The amount of confidence and competence a person has in making their own healthcare decisions and the trust they have in the expertise of their healthcare team can affect their self-management choices (Thorne 1990). Factors affecting self-management choices include the quality of interactions with healthcare professionals (Vermeire et al. 2003), service availability (Zigbor & Songer 2001), individuals own concerns (Nyhlin 1990; Gillibrand & Flynn, 2001; Vermeire et al. 2003), and gender differences (Hepworth 1999; Koch, Kralik & Taylor 2000). Several studies have identified that poor knowledge and explanations by health professionals contribute to patient difficulty in implementing optimal diabetes care (Rasmussen, Wellard & Nankervis 2001; Vermeire et al. 2003).

Service availability for people with diabetes is also a barrier to effective diabetes management. In rural/regional areas particularly, there are limited numbers of skilled healthcare professionals with expertise in diabetes care (AIHW 2004a; 2004b). Consequently service providers are hard to access, have long waiting lists and are frequently costly (Zigbor & Songer 2001). This study therefore sought to understand how people managed their diabetes in this context.

## Methods

Using a qualitative interpretive approach, this study explored peoples' experiences of managing their type 2 diabetes in regional communities (Thorne et al. 1997). Four individuals aged 55 - 65 years [3 females, 1 male], who had been diagnosed with type 2 diabetes for at least two years, and were able to understand and speak English responded to advertisements in a local newspaper. Pseudonyms are used to maintain the confidentiality of the participants.

In depth, semi-structured interviews provided an opportunity for obtaining participants perspectives (Kvale 1996) and were conducted by one of the team (SR). Interviews were conducted at a central venue in a regional city following approval from the university Human Research Ethics Committee. The interviews included broad demographic questions related to age, family and social circumstances, and were followed by discussion of issues related to type 2 diabetes management and community based services. A strategy of using summarising comments in the interviews was adopted as a means of data validation, where the interviewer's interpretation of the participant's view was confirmed (Rubin & Rubin 1995). All interviews were tape-recorded and later transcribed by one of the team (SR). A reflective research journal was also used to record participants' non-verbal cues and the interviewer's impressions

Analysis began during the data collection when interviews were converted to text by verbatim transcription (Wellard & McKenna 2001), allowing emergent concepts and themes to inform subsequent interviews (Rubin & Rubin 1995). The

transcripts were read and reread to become deeply familiar with each participant's account of their experiences of living with diabetes.

## **Findings**

Participants spoke of limitations in access and quality of community based services. Stories were told of how family relationships, alternative sources of information and food choices influenced the way participants lived with diabetes. The four predominant themes identified were community based services, family relationships, and food as a social connector and strategies that might help others.

### **Community Based Services**

All participants described their GP as central in the overall management of their diabetes, visiting regularly for monitoring of their diabetes, routine blood testing, and to discuss issues in their self-care practices. Kelly routinely accessed her GP and perceived him as a great support in the management of her multiple co-morbidities.

*“The GP, I see regularly on about a 3 weekly basis, because something always turns up. I need to catch things early.”*

Participants had used other community based services (such as, podiatrist, dietician) following referral when first diagnosed. However, they did not routinely use these services after their initial diagnostic phase. The regularity of attendance and use of community based services varied amongst the participants. This was in part influenced by their degree of acceptance of their diagnosis and perceived need for support. Two participants discussed how they had denied their diagnosis and therefore had limited use of community services. Jill, for example, spoke of making little change to her unhealthy food choices and was inconsistent in BGL monitoring.

*“Well, I know I have it, yet because I can’t see it, and no sort of immediate effects. Hey, it is just something that I just don’t want to have, you know so I would have to put in denial as part of the problem.”*

Other barriers to using community based services were reportedly related to limited service availability and the inadequate quality of services provided. In regional Victoria the number of diabetes educators, podiatrists and dieticians is limited. Many service providers described by participants in this study catered for several communities and waiting lists for service were common. As Jill said:

*“She [diabetes educator] is very busy and works over 4 campuses. That sort of deters you from actually going ahead and really grabbing the moment to go and see her and make an appointment.”*

Both podiatry and dietetic services were described as costly, and the attitudes of the professionals deterred regular use. One participant had attempted to see her podiatrist regularly as recommended, but found the podiatrist wanted to cancel her appointments. The podiatrist argued that there were patients with more serious problems than those who just wanted regular checks but had no obvious problems. Similarly participants discussed issues associated with dieticians. Dietetic services were reported as not adding new knowledge and furthermore, inexperienced young dieticians contributed to the participants’ frustration. Jill, who was over weight, described the approach of the dietician as a barrier. The youthful inexperience and the thin appearance of the dieticians made her feel that there was little empathy with her difficulties.

*“They were thin and looked after themselves. I found the communication style was lacking. Maybe if it was someone who had actually been through some problems and understood what it is like to find it difficult. I think it might have helped then.”*

A further issue relating to dietetic advice was a perceived constant change in ideas about food and diet, which made learning about healthy eating difficult. Phil commented:

*“Um, I found them to be a bit confusing because it seems the sort of flavour of the month changes from year to year.”*

All participants were self-sufficient in selecting diabetes information resources that suited their needs and kept them informed. They used a range of media to inform themselves about diabetes. Television and the internet were popular sources of information. Phil and Kelly both related stories of learning from scientific reports of advances in health and diabetes care. Two participants attended sessions at their local community health centres. Most of the participants were members of Diabetes Australia; although they used it infrequently they were aware of its resources as they all were members of the National Diabetes Service Scheme (NDSS) to receive discounts on diabetes related supplies.

### **Family Relationships**

Participants described how support or the lack of support from immediate and extended family affected their diabetes self-management choices. Support was an important outcome given that participants had limited access to community services.

Spousal relationships were very supportive for all participants and seen by their encouragement to continue ‘healthy eating’, physical activity and their willingness to accompanying them to healthcare appointments. Spouses were reported as active in discussing food choices and meal sizes. Spouses also encouraged their partners to be active and engage in life.

*“My wife for instance always makes sure that whatever I eat is or has the minimal amount of sugar in it. We also walk together. There is a forest near us and we often go walking with the dog.”*

Accompanying patients to their healthcare appointments helped because the spouse would ask questions and take in things they might miss. As Kelly reported:

*“He is very observant and notices things and comes to the doctor with me.”*

Concern from their family was prominent in participants' accounts. Many worried about the genetic potential for their family members to also develop type 2 diabetes. Consequently participants described the importance of increasing the awareness of their children and grandchildren about diabetes issues and the need to practise healthy eating activities.

*“I have my grandkids come over for tea quiet regularly and they will say to me that tea was nice, beautiful. I say to them and what else was it? And they say healthy, yes, yeah.”*

### **‘Food’ as a social connector**

Food was identified as an important factor in the lives of participants and influenced their social relationships. Dietary restrictions often made participants feel uncomfortable at social events, as they had to decide whether to accept offered foods that were not healthy choices. Laura felt embarrassed when visiting friends, as the food offered was often unsuitable. She suggested that people with diabetes may not want to draw attention to having an illness that requires dietary restrictions.

*“It’s a little bit embarrassing, they will offer you something that you don’t want and then you say well have you got a tin of tuna in the cupboard or a tin of baked beans.”*

Other participants reported feeling less embarrassed but still had to find healthy alternatives and turn down offers of cake. They reported often feeling judged about



their food choices by family and friends who seemed unaware of their diabetes and dietary needs.

Participants also conveyed a belief that people in the general community lack awareness about diabetes dietary routines and factors that affect their management practices. This lack of awareness extends to the various reasons why BGLs may fluctuate, including illness, stress and physical activity. All participants developed their own strategies to overcome food barriers in social situations. Phil suggested that overcoming problems about food when dining out can be made less stressful by telling others you have diabetes. Laura took her own snacks with her when visiting relatives.

### **Strategies to help others**

Participants were asked to contribute ideas or topics that may help other people with diabetes. Three particular views were suggested by participants; DSME programs, the availability of a diabetes counsellor and diabetes awareness strategies targeted at school children. Jill proposed a need for self-management programs in regional areas that should include input from GPs, diabetes educators, dieticians and podiatrists, in the one centre. She believed that if these programs were available to her at diagnosis, it would have been a better support for her. She suggested these programs could include exercise, cooking and general discussion classes that people could attend and which may make living with diabetes less difficult.

Phil argued that diabetes awareness needed to be more targeted; extended beyond the broad community and diabetes groups. He believed diabetes awareness and healthy eating should be targeted at school age children. Several of the

participants raised the issue of childhood awareness of diabetes and education for healthy eating. They argued of the importance of making children aware that looking after their bodies and incorporating exercise and healthier food choices can prevent them developing type 2 diabetes in the future.

### **Discussion**

Our findings support the literature that indicates regional services to support people with type 2 diabetes in Australia are inadequate. Delays in accessing services range from several weeks to months, leaving participants feeling unsupported. Limited access to specialist diabetes professionals in their regional areas means that people have to travel long distances for specialist care. These findings are reflected in national reports that show people with diabetes lack access to general and specialist services and opportunities to seek key healthcare professionals (AIHW 2004a, 2004b). This is of concern given that the incidence of type 2 diabetes has doubled in regional Australia in the past 15 years (Simmons & McKenzie 2005).

Participants primarily used their local GP for support. Several other studies have identified the GP as central in diabetes management (Willson 2001, Young et al. 2005). These findings are significant because a reliance on GPs may put this group at increased risk due to a continuing decline in regional and rural GPs (AIHW 2004a; Overland, Yue & Mira 2001; Van Eyk & Baum 2002).

The quality of services provided to people with type 2 diabetes in this study were reported as sub optimal, often providing little support and influencing peoples' subsequent use of services and adoption of self-management practices. Participants reported difficulties in making appointments and perceived healthcare providers as

unsupportive with negative attitudes, who offered limited acknowledgement of participants' perceptions. There is minimal research relating to service quality and content provided to people with diabetes in Australia. In a US study, Pasley et al. (2005) found that people with less than adequate control of their diabetes management were dissatisfied with the services provided to them. Another international examination of patient/provider psychosocial barriers to diabetes management (Peyrot et al. 2005) found providers recognised patient worries but did not have the time, skill or resources to manage these problems. Our findings are reflective of these studies.

Participants in this study reported that there were minimal opportunities to access self-management programs in their regional setting. DSME programs have been shown as successful in providing clients with the necessary skills to help them better self-manage their diabetes. DSME programs are arguably ideal for rural and regional populations because they can be tailored to suit individuals needs (Renders et al. 2001; Norris et al. 2002; Lorig & Holman 2003), yet they are seldom available in regional and rural settings. Chronic care services, healthcare professionals and DSME programs need to be improved in all regional community settings to help reduce the barriers participants experience in utilising services.

The level of family and social support people receive has significant influence on their diabetes self-management practices (Delamater et al. 2001; Gallant 2003). Participants in the current study noted the importance their spouses played in supporting healthy eating, physical activity and attending healthcare services. Participants also reported their perceived judgements of others about their food

choices in social situations impacted upon their self management. Similarly, Koch, Kralick and Sonnack (1999) found people with diabetes often feel left out and uncomfortable at social occasions. Social stigma has been frequently reported as experienced by people with chronic illnesses (Wellard, 1997; Joachim & Acorn 2000; Shiu, Kwan and Wong 2003). Stress arising from experiences of stigma can result in diminished quality of life, affect the quantity and quality of healthcare accessed (Berger, Wagner & Baker 2005), which in turn influences a person's acceptance and management of their illness (Miller & Kaiser 2001).

## **Conclusion**

This study has identified the four areas of community based services, family relationships, food as a social connector and strategies that might help others that participants identified as influential in their self management of their diabetes. Raising awareness about diabetes, its impact on people in social situations was argued by participants as an important strategy to help improve social relationships and self-management choices for people with diabetes. Health promotion campaigns led by nurses could help to dispel common community misconceptions about diabetes and psychosocial aspects of living with the illness (Hjelm, Mufunda, Nambozi & Kemp 2003; Shiu et al. 2003; Le-Gales Camus 2005). Improving the knowledge of healthcare professionals about diabetes and the impact of issues of social stigma and dietary management is also needed.

Further research is needed into the delivery of chronic care services in regional and rural Australia. This study has highlighted barriers a small number of people experienced which warrant further exploration in a larger study. There is also a need

to explore the applicability of the principles of the National Diabetes Strategy (Australian Government Department of Health and Ageing, 1999) for people living in regional and rural Australia where access to specialist teams is limited.

## References

- Ah Kit J, Prideaux C, Harvey PW, Collins J, Battersby M, Mills PD, and Dansie S (2003) Chronic disease self-management in Aboriginal communities: Towards a sustainable program of care in rural communities. *Australian Journal of Primary Health* 9(2-3): 168-176.
- Australian Government Department of Health and Ageing (1999) National Diabetes Strategy 2000-2004. Commonwealth of Australia, Canberra.
- Australian Institute of Health and Welfare (AIHW) (2002) *Diabetes: Australian facts 2002*, AIHW, Canberra.
- Australian Institute of Health and Welfare (AIHW) (2004a) *Australia's Health 2004*. AIHW, Canberra.
- Australian Institute of Health and Welfare (AIHW) (2004b) *Health system expenditure on disease and injury in Australia, 2000-01*. AIHW, Canberra
- Berger M, Wagner TH, and Baker IC (2005) Internet use and stigmatised illness. *Social Science & Medicine* 61(8): 1821-1827.
- Bodenheimer T, Lorig K, Holman H, and Grumbach K (2002) Patient self-management of chronic disease in care. *Journal of the American Medical Association*, 288(19): 2469-2475.
- Delamater AM, Jacobson AM, Anderson B, Cox D, Fischer L, Lustman P, Rubin R, and Wysocki T (2001) Psychosocial therapies in diabetes. *Diabetes Care* 24: 1286-1292.
- Dunstan DW, Zimmet PZ, Welborn, TA, De Courten MP, Cameron AJ, Sicree RA, Dwyer T, Colagiuri S, Jolley D, Knuiman M, Atkins R, and Shaw JE (2002) The rising prevalence of diabetes and impaired glucose tolerance: The Australian diabetes, obesity and lifestyle study. *Diabetes Care* 25: 829-834.
- Engelgau MM, Narayan KM, Venkat S, Jinan B, and Vinicor F (2003) Addressing the burden of diabetes in the 21<sup>st</sup> century: Better care and primary prevention. *Journal of the American Society of Nephrology* 14(7): (S88-S91).
- Gallant MP (2003) The influences of social support and chronic illness self-management: A review and directions for research. *Health Education and Behaviour* 30(2): 170-195.
- Gillibrand W and Flynn M (2001) Forced externalization of control in people with diabetes: A qualitative exploratory study. *Journal of Advanced Nursing* 34(4): 501-510.
- Harmel AP, and Mathur R (2004) *Davidson's Diabetes Mellitus: Diagnosis and Treatment* (5th ed) Saunders, Pennsylvania.

- Hepworth J (1999) Gender and the capacity of women with NIDDM to implement medical advice. *Scandinavian Journal of Public Health* 27: 260-266.
- Hjelm K, Mufunda E, Nambozi G, and Kemp J (2003) Preparing nurses to face the pandemic of diabetes mellitus: A literature review. *Journal of Advanced Nursing* 41(5): 424-435.
- Holman H and Lorig K (2004) Patient self-management: A key to effectiveness and efficiency in care of chronic disease. *Public Health Reports* 119(3): 239-244.
- Joachim G and Acorn S (2000) Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing* 32(1): 243-248.
- Knuiman MW, Welborn TA, and Bartholomew HC (1996) Self-reported health and use of health services: A comparison of diabetic and nondiabetic persons from a national sample. *Australian and New Zealand Journal of Public Health* 20(3): 241-247.
- Koch T, Kralik D, and Sonnack D (1999) Women living with type 2 diabetes: The intrusion of illness. *Journal of Clinical Nursing* 8: 712-722.
- Koch T, Kralik D and Taylor D (2000) Men living with diabetes: Minimising the intrusiveness of the disease. *Journal of Clinical Nursing* 9(2): 247-254.
- Kvale S (1996) *Interviews: An introduction to qualitative research interviewing*: Sage: Thousand Oaks.
- Le-Gales Camus C (2005) Fighting chronic disease. *Bulletin of the World Health Organization* 83(6): 407-409.
- Linekin PL (2003) Home health care and diabetes assessment, care, and education. *Diabetes Spectrum* 16: 217-222.
- Lorig KR, and Holman HR (2003) Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioural Medicine* 26(1): 1-7.
- Lorig K, Ritter P, Stewart AL, Sobel DS, Brown BW, Bandura A, Gonzalez VM, Laurent DD and Holman HR (2001) Chronic disease self-management program: 2 year health status and health care utilisation outcome. *Medical Care* 39(11): 1217-1223.
- Miller CT and Kaiser CR (2001) A theoretical perspective on coping with stigma. *Journal of Social Issues* 57(1): 73-92.
- Nocon A, Rhodes PJ, Wright JP, Eastam J, Williams D, Harrison RR and Young RJ (2004) Specialist general practitioners and diabetes clinics in primary care: A qualitative and descriptive evaluation. *Diabetic Medicine*, 21(1): 32-39.
- Norris SL, Lau J, Smith SJ, Schmid CH and Engelgau MM (2002) Self-management education for adults with type 2 diabetes. *Diabetes Care*, 25: 1159-1171.
- Nyhlin KT (1990) A contribution of qualitative research to a better understanding of diabetic patients. *Journal of Advanced Nursing* 15: 796-803.
- Overland J, Yue DK and Mira M (2001) Use of Medicare services related to diabetes care: The impact of rural isolation. *Australian Journal of Rural Health*, 9: 311-316.
- Pasley B, Roohan PJ, Wagner V, Novak J and Gesten F (2005) Identifying areas for improvement: Results of a medicaid managed care diabetes survey. *Journal of Health Care for the Poor and Underserved* 16(4):, 691-720.

- Peyrot M, Rubin RR, Lauritzen T, Snoek, FJ, Matthews DR, and Skovlund, SE (2005) Psychosocial problems and barriers to improve diabetes management: Results of the Cross-National Diabetes Attitudes, Wishes and Needs (DAWN) Study. *Diabetic Medicine* 22(10): 1379-1385.
- Rasmussen B, Wellard S, and Nankerveris A (2001) Consumer issues in navigating health care services for type 1 diabetes. *Journal of Clinical Nursing*, 10: 628-634.
- Renders CM, Valk GD, Franse LV, Schellevis FG, Van Eijk JT and Van Der Wal G (2001) Long term effectiveness of a quality improvement program for patients with type 2 diabetes in general practice. *Diabetes Care*, 24: 1365-1370.
- Rubin HJ and Rubin IS (1995) *Qualitative interviewing: The art of learning data*. Sage, Thousand Oaks.
- Russell LB, Churl Suh D and Safford MM (2005) Time requirements for diabetes self-management: Too much for many? *The Journal of Family Practice* 54(1): 52-56.
- Schmidt LA (2003) Patient's perceptions of nursing care in the hospital setting. *Journal of Advanced Nursing*, 44(4): 393-399.
- Shiu ATY, Kwan JJYM and Wong RYM (2003) Social stigma as a barrier to diabetes self-management: Implications for multi-level interventions. *Journal of Clinical Nursing* 12: 149-150.
- Simmons D, McKenzie A, Eaton S, Shaw J and Zimmet P (2005) Prevalence of diabetes in rural Victoria. *Diabetes Research and Clinical Practice* 70(3): 287-290.
- Steed L (2005) Evaluation of the UCL diabetes self-management program (UCL-DSMP): A randomized controlled trial. *Journal of Health Psychology* 10(2): 261-276.
- Thorne SE (1990) Constructive non-compliance in chronic illness. *Holistic Nursing Practice* 5(1): 62-69.
- Thorne S, Kirkham SR and MacDonald-Emes J (1997) Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing and Health* 20: 169-177.
- Van Eyk H and Baum F (2002) Learning about interagency collaboration: Trialling collaborative projects between hospitals and community health services. *Health and Social Care in the Community* 10(4): 262-269.
- Vermeire E, Van Royen P, Coenen S, Wens J and Denekens J (2003) The adherence of type 2 diabetes patients to their therapeutic regimens: A qualitative study from the patient's perspective. *Practical Diabetes International* 20(6): 209-214.
- Wellard S (1997) Constructions of chronic illness. *International Journal of Nursing Studies* 35: 49-55.
- Wellard S and Mc Kenna L (2001) Turning tapes into text: Issues surrounding the transcription of interviews. *Contemporary Nurse* 11(2-3): 180-186.
- Willson T (2001) What do your patients with diabetes want? *Current Therapeutics Suppl.* 13(20-1): 23-35.

- World Health Organization (WHO) (2004) *Diabetes action now: An initiative of the World Health Organization and the International Diabetes Federation.*: WHO, Switzerland.
- Yip JY, Myrtle RC, Wilber, KH and Grazman, DN (2002) The networks and resource exchange in community-based systems of care. *Journal of Health and Human Services Administration* 25(1/2): 219-259.
- Young AF, Lowe JM, Byles JE and Patterson AJ (2005) Trends in health service use for women in Australia with diabetes. *Australian and New Zealand Journal of Public Health* 29(5): 422-428.
- Zgibor JC and Songer TJ (2001) External barriers to diabetes care: Addressing personal and health systems issues. *Diabetes Spectrum* 14: 23-28.