

Living with type 2 diabetes: 'Putting the person in the pilots' seat'

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KEY WORDS

Type 2 diabetes, Self-management, Primary Health Care, Control.

ABSTRACT

Objective

To better understand the day-to-day lived experiences of those adults with type 2 diabetes, in particular, their historical and current ability to self manage this condition.

Design

This qualitative study utilised aspects of both phenomenology and grounded theory to inform the study design, namely an iterative thematic content data collection and analysis process. This enabled the identification of emerging themes.

Setting

Sample subjects all resided in Whanganui, New Zealand and were interviewed either in their own home, workplace or in a private room at the Whanganui Regional Primary Health Organisation.

Subjects

Nine in depth interviews were conducted with a purposively selected sample of adults living with type 2 diabetes; five females and four males; four New Zealand Europeans, four Māori and one Samoan. Years since diagnosis ranged from one to twenty three.

Results

The results demonstrate similarities between this research and that conducted internationally in terms of the impact of the diagnosis of type 2 diabetes and the difficulties adopting and adapting to the complex self care tasks required to manage this chronic condition on a daily basis. Support to self manage in this study was harnessed more readily from spiritual beliefs, family and friends rather than from health professionals.

Conclusion

Development of a sense of ownership or control of the condition is paramount to enable people to self manage effectively on a day to day basis and is determined primarily by the individual's personal support systems. The primary focus of care should therefore be on the 'person', their story, needs and support systems, including the provision of health services and educational programs, well versed with and reflective of the broad principles of self management in a multi cultural environment.

INTRODUCTION

Chronic conditions are an increasingly major burden and a challenge to health care systems due to ageing populations, food consumption patterns and changes in lifestyle behaviours (Horsburgh et al 2007). Worldwide the number of people with diabetes is increasing and a similar trend is occurring locally with prevalence projections indicating that by the year 2021, there will be 380,000 people with diabetes in New Zealand (MOH 2006). Type 2 diabetes is the more common of the two main types as it affects 85%-90% of all those diagnosed (NZGG 2003). This type may also be under reported as it is commonly undiagnosed until the disease process is well advanced, as it is often asymptomatic in the earlier stages.

The incidence and prevalence of diabetes is further exacerbated by demographic and socio cultural factors such that, those in minority ethnic groups, namely Māori and Pacific Island people, are more at risk of diabetes but receive differential treatment from current health services leading to increased rates of complications and mortality (Joshy and Simmons 2007; MOH 2001; Simmons et al 1998). The New Zealand Primary Health Care Strategy (PHCS) was launched in 2001 partly in response to these inequalities and a growing concern that the overall health status of New Zealander's was "slipping behind other developed countries" (MOH 2000, p. 3). A strengthened primary health care sector was considered by politicians and health policy analysts a requirement to facilitate improved chronic care health outcomes.

As part of restructuring health systems, models such as the Expanded Chronic Conditions Model (ECCM) (Barr et al 2003) suggest that a broad approach to the management of chronic conditions is required, where there is increased focus on community participation, integration of health care providers, and inter sectoral activity, with the person and their family placed at the centre. Inherent to the overall success of the ECCM is the concept of self management.

Self management is defined as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition" (Newman et al 2004, p. 1523). It is assumed that this broad concept of self management is well understood and widely practiced by both patients and health practitioners as it is perceived to be the mainstay of chronic care management (Holman and Lorig 2004). However, there are wide variations in the abilities of individuals to self manage their condition effectively. There can also be reluctance on the part of some health professionals to acknowledge that 'their' patient actually knows their own condition quite well and can manage it on a daily basis with minimal assistance (Cheek and Oster 2002). Viewing the ongoing care in terms of a 'partnership' can be a new challenge. A 'role reversal' is required for effective self management so that the patients become the experts and the provider the mentor (Ellison and Rayman 1998).

A component of self management is learning about and adopting the lifestyle interventions in relation to dietary habits and exercise; considered essential to prevent or minimise complications (NZGG 2003). These interventions are often the most difficult aspects to adhere to or comply with (Nagelkerk et al 2006). Negative emotions such as anger, shame, guilt and denial can impact on this process (Rapaport et al 2000). Therefore an increased focus needs to be placed on the psychosocial issues related to living with the condition in order to improve the health and quality of life for people with diabetes (Skoveland 2004).

Several authors have highlighted the staged approach to self management, in particular adapting to and managing to gain control or 'mastery' over diabetes. This can start with the initial reactions by patients at the time of diagnosis and the successful early acquisition of knowledge about diabetes and self care. Following on, it is necessary to 'become engaged' and to develop strategies to become an 'expert'. Finally, for some, a state of 'integration' or

sense of balance is reached which allows acceptance of self as a person with diabetes (Koch et al 2004; Whittemore et al 2002; Ellison and Rayman 1998; Paterson et al 1998). Support to do so is sought from a variety of avenues such as family and friends, health services, educational programs, spirituality and consumer support groups.

Little is known about the success or otherwise of patients with type 2 diabetes in gaining such 'mastery' and 'integration' in current New Zealand primary care settings. This study aimed to explore individual patients' experience of such processes, from and around the time of diagnosis and over subsequent months or years.

METHOD/METHODOLOGY

This qualitative study combined aspects of both grounded theory and phenomenological approaches to explore the experiences of the resultant nine participants living with type 2 diabetes in Whanganui, New Zealand.

Both phenomenological and grounded theory methodologies share a common focus on the "richness of human experience, seeking to understand a situation from the subject's own frame of reference and use flexible data collection procedures" (Baker et al 1992, p. 1355). However, as these two methodologies have developed from different 'intellectual roots' in philosophy and sociology, their research strategies are different. Aspects from both approaches, rather than a separate or fully integrated approach have been used in this research. Phenomenology aims to learn and construct "the [objective] meaning of a human experience through intense dialogue with the persons who are living the experience" (Beanland et al 1999, p. 245). The intent here however, was to investigate 'through intense dialogue', but not critique, the subjective experiences of people living with type 2 diabetes whilst also wishing to investigate the social processes for these same participants. Thus some aspects of the grounded theory methods were used to analyse the data in order to develop themes from the dialogue, followed by a content analysis approach to identify the emerging themes (Boyatzis 1998).

A purposive, or a non probability sampling strategy, (Beanland et al 1999) was used to select participants because they were considered to be typical of the study population group and deemed 'information rich' for the purposes of the study (Sandelowski 2000). The proposed sample consisted of adults between the ages of thirty and sixty who had been diagnosed with type 2 diabetes for more than a year, and who had no dominant coexisting health issues. Consideration was given to ethnicity to ensure that the sample was broadly representative of the Whanganui diabetes population statistics. (In the Whanganui region, approx 20% of the population self identify as Māori, and 1% as Pacific Island people, with the majority identifying as NZ European). Furthermore, Māori and Pacific Island people with type 2 diabetes are over represented in the diabetic population within the age range specified for this study (47% Māori; 4% Pacific Island people) (Rayner 2007).

In order to identify prospective participants, the research proposal was initially outlined at a monthly staff meeting to a broad group of primary health care practitioners aligned to the Whanganui Regional Primary Health Organisation (WRPHO). These practitioners explained the project to prospective patient participants, using a written information sheet to explain the project during their initial discussions with them. Every effort was made to ensure that prospective participants were invited to participate without coercion, and were reassured that the clinical care they received would not be compromised if they did not agree to participate. Once prospective participants had been identified by primary care providers, the interviewer researcher (JH) then contacted the potential participant by phone, checked their agreement to participate and if appropriate, arranged an interview time at a place and time suitable to the participant.

At the time of the interview, written consent for the interview process was obtained, and all participants readily agreed to audio recording of the interviews. Prior to the start of each interview, which ranged in duration from approximately 45 minutes to just over one hour. Participants were thanked for their participation and given a 'koha' (\$20 petrol voucher)

(a small gift of appreciation which is common cultural practice for both Māori and Pacific Island people and considered appropriate for culturally safe research).

This process respected the concept of cultural safety that acknowledges the diversity in worldviews which exist both within and among different cultures including those grouped by gender, social, religion and ethnicity (Nursing Council of New Zealand 2005). Cultural safety was guided by one of the researchers, who is an indigenous researcher and director of a Māori research centre in Whanganui. Cultural advice was also sought from the WRPFO employed Pasifika and the Māori High Needs nurses. In addition, both the Whanganui based Pasifika Forum group and the Whanganui Region Māori health representatives were consulted about the study prior to commencement.

All interviews were conducted by one of the authors (JH), using a semi structured interview technique, interwoven with an iterative analytic process. Data saturation, where themes occurred and recurred, was reached after nine interviews had been conducted. The data were transcribed by a professional transcriber. Anonymised transcripts were reviewed by all three researchers, and themes generated by the analysis checked and rechecked.

A summary of the emergent themes was produced and sent to all participants for validation, an accepted method of member checking (Mays and Pope 1995) for data corroboration. Participants were asked to reply if they wished or disagreed with the summary of these findings; non response was taken as tacit agreement. In the event two interviewees replied and had no disagreement with the suggested themes.

Ethics approval for this research was granted by the Central Regional Ethics Committee (Ministry of Health, Wellington).

FINDINGS

Participants

The nine participants included four New Zealand Europeans, four Māori and one Pacific Island person

(Samoan). Five were females and four were males with an age range of forty three to seventy nine years. Time since diagnosis ranged from one to twenty three years. All, bar one participant who required daily insulin, used oral diabetes medication and dietary measures to maintain glycemic control.

Themes

Seven data categories were developed from the data and subsequently evolved to become three themes: 'loss of control', 'gaining control' and 'being in and staying in control'.

Loss of control

The first theme, 'loss of control' encompassed the time of diagnosis when alongside the physical symptoms of diabetes there are also the emotional factors which together impact on the person's state of equilibrium. All of the participants vividly recalled the events surrounding the diagnosis and reported experiencing a range of reactions from denial, shock, fear, and anger:

I was afraid and I thought oh, better I go and kill myself (Interview 7: 71 year old, Pacific Island male),

and relief;

...it was probably a relief, if you like, to find out there was something. You think oh I might be losing my mind (Interview 4: 48 year old Pakeha female).

Some of the predisposing factors which contribute to the development of diabetes such as age and family background, were also beyond the control of some participants:

I fit the category because I'm forty, I'm Māori, a prime candidate and I was very overweight (Interview 1: 51 year old, Māori female).

Gaining control

The process of 'gaining control' through adoption of lifestyle changes is required to manage this newly imposed complex condition which can be challenging and time consuming. Sometimes everything goes well, but there are also times when it is just hard work and barriers and tensions result in limited progress (Cheek and Oster 2002; Polonsky 1999). These difficulties were reiterated by most of the

participants in this study and are compounded by the realisation that the rewards for modifying lifestyle habits are not evident or tangible enough in the short term. Thus, as the reasons for embracing the complex management tasks and lifestyle changes wholeheartedly are not evident, there is often little motivation for some to do so:

It takes work. Its actually work. And you don't get paid for it. Your body is kind of undemanding until it breaks down I think, isn't it? You kind of think well I don't feel that bad so therefore I can carry on. But I know I can't.

The same participant said:

You don't feel unwell. If I felt unwell that would motivate me (Interview 2: 43 year old, Pakeha female).

Some also spoke of the temptations they faced:

It's actually harder than I thought it would be...as soon as I see people eating what I shouldn't be eating.I just go gorge myself (Interview 9: 48 year old Māori male).

Being in and staying in control

The third theme, 'being in and staying in control' reflects the development of a sense of empowerment and integration or acceptance of diabetes, which was enhanced for the Māori and Pacific participants by their spiritual beliefs and visions:

A man without a vision is just going to walk around the mountain all the time...a man with a vision will climb the mountain (Interview 8: 43 year old Māori female).

Despite the progression of diabetes complications and difficulties regaining glycaemic control through medication changes, there was a sense that these setbacks were expected and that due to the prior development of skills, knowledge, confidence and support, balance could once again be achieved:

Its really up to me. And nobody can do it for me. So you plod along (Interview 3: 56 year old, Pakeha female).

DISCUSSION

This exploration of patients' experiences of being diagnosed with, and subsequently living with, a chronic condition such as diabetes, has identified three predominant themes: loss of control; gaining control and being in and staying in control. This concept of control predominated and infiltrated all of the categories, from the predisposing factors leading to the diagnosis, the struggle to adapt to the daily management regimes required, through to the ability of the individual to achieve a balance between living with a progressive chronic condition and living a 'normal' life. The word 'control' occurred and was recurrent in nearly all of the interviews, perhaps reflecting an underlying wish or need to control their condition which the interviewees may or may not be fully aware of.

The data reinforces the notion that not only is the time of diagnosis a major event in the lives of most individuals and their families, but that subsequent management and mastery is also complex and affected by multiple factors. Participants in this study spoke about the time of diagnosis as being traumatic and life changing. Tailored support and information at this time is thus imperative to enhance the ability of individuals and their families to come to terms with the diagnosis, to gain a basic understanding of the condition, to debunk the myths and to clarify treatment regimes. All are key components to enhance the adoption of new behaviours necessary to start the 'diabetes journey' (Caccioppoli and Cullen 2005; Peel et al 2004; Cheek and Oster 2002). The participants in this study were unable to identify or remember being offered or gaining access to this type of comprehensive support at the time of diagnosis.

While all participants had had some initial contact with a dietician and diabetes nurse, the content of the information relayed appeared to be 'disease and task specific' rather than a broader self management learning experience. Clarke and Goosen (2005) found that merely providing information about the condition

and its seriousness is highly unlikely to result in enhanced adherence to treatments. Participants in this study had either ignored the advice, modified it to suit their lifestyles or had attempted to be more vigilant with regards to some but not all aspects. These episodes of inconsistency with the recommended regimes reflect the difficulties of adjusting to the complexities of the required tasks, as well as limited knowledge. The consequences of non adherence are exhibited both in terms of clinical and psychological outcomes, the latter, often in the form of guilt, anxiety and frustration as was reflected by some participants in this study.

Alternatively, a comprehensive approach from the outset which embraces the concept of self management, whereby the person and their family play a central role, monitor symptoms, make informed decisions, and adhere to treatment regimes developed in partnership with key health professionals is believed to be more effective (Bycroft and Tracey 2006). To enhance this process monitoring tools, behaviour change techniques, health and wellness plans alongside disease specific and empowerment education, are considered to be key components for successful self management (Tracey and Bramley 2003).

The results from this study suggest the health services experienced by the participants are challenged by the task of providing comprehensive and outcome based self management support and care. Most participants had very limited contact with their general practice team (similar to Pooley et al's findings 2001) and the opportunity to address more than the obvious clinical issues could be seen to be yet another challenge within the current primary care practice environment (Pooley et al 2001).

Perhaps in lieu of health professional support, most participants had instead harnessed family and friends, as well as cultural and spiritual beliefs to provide the impetus needed to gain some control of their lives and ownership of the condition; such that a state of integration for some was achieved. However, as the condition progresses, this measure of control is constantly being challenged and those

best prepared to adapt to this are those who have developed a higher degree of self management ability acquired through enhanced social support systems and inner resources.

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

This study, drawing on the experiences of a selected sample of people living with type 2 diabetes, highlighted a number of concerns regarding primary health care services in Whanganui, New Zealand.

Primary health care services accessed by the participants were not maximising opportunities to work with patients and families to assist patients to manage their condition or as the participants stated to help them 'stay in control'. Limited support at the time of diagnosis, limited recognition of the need for truly patient centred planning, limited utilisation of evidence based tools to facilitate and support behaviour change were all barriers to enabling patient self management. As a result some patients were not able to sustain the changes required to 'stay in control'.

These findings have considerable implications for practice. Health care teams need to be well organised, and expertise in self management support urgently developed. Developing the roles and responsibilities of the whole health team and especially that of the nurse should be considered paramount to achieve successful implementation of self management practices, along with recognition of the individual diversity and contextual factors impacting on each person.

Key to the ultimate success however, is not only the implementation of these processes but the abilities of those 'on the ground' to respond to and understand the reality and the abilities of those living with this chronic condition. This understanding will better assist people with diabetes to engage, to gain control and to remain engaged, to develop a sense of personal balance and to stay in control. Putting these people and their families at the centre of their health care team, surrounded by broader systems and processes which enhance the management of

chronic conditions, is essential to achieve better health outcomes.

LIMITATIONS

These results pertain solely to the data collected during the interview sessions as the researcher (JH) had no access to the clinical data relating to these nine participants and no additional tests or scores were undertaken alongside the interviews to provide corroborative evidence. Thus the participants' honesty is not questioned and their responses are based on their understanding and experiences. In addition, as this was a qualitative study with a small number of participants, these findings are not necessarily generalisable throughout the diabetes population.

Although all of the interviews were conducted by one researcher (JH); herself a health professional (experienced primary health care nurse), this allowed for good inter interview reliability, and enabled an ongoing iterative process to develop over the course of the data collection.

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