

Diabetes self-management experience: a focus group study of Taiwanese patients with type 2 diabetes

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Aims and objectives. The purpose of this study was to understand and document the perspectives of Taiwanese patients with type 2 diabetes regarding the processes and strategies used to self-manage their chronic condition.

Background. The importance of patients learning self-management through self-regulation has been recognized in the literature, but little of this research has focused on skills to manage symptoms. Besides, studies about how patients self-manage their diabetes in term of patients' perspectives have been scant. Socio-cultural context is also an influencing factor in disease management.

Methods. Focus groups were used to collect data from 41 adult participants with type 2 diabetes at three teaching hospitals located in southern Taiwan. The five focus groups ranged in size from six to ten people. The focus groups were recorded, transcribed and analysed.

Results. Three themes and ten subthemes were revealed. The first theme 'the impact of the illness' includes three subthemes: facing the predicament of stigmatization, concern about inheritance of diabetes and seeking alternative therapy for hope. The second theme 'self-regulation process' includes four subthemes: struggling for diet control, adjusting to psychological barriers, identifying body response and developing strategies for dealing with diabetes. The third theme 'transformation process' includes three subthemes: resuming conventional

illness, support from families and fellow patients and learning to live with the disease.

Conclusions. Findings obtained from the themes of the study illustrated that self-management of patients with diabetes is highly related to their own sociocultural environment and experiences. Understanding the cultural features and the meaning of illness can help in the development of interventions tailored to the needs of this cultural group.

Relevance to clinical practice. The findings have important implications for healthcare providers to consider individuals' sociocultural backgrounds in which they make choices about their treatment and manage their illness. This recognition will enhance patients with diabetes to transform being active in self-management through the skills of self-regulation.

Key words: diabetes, focus group, nurses, nursing, self-management, Taiwan

Introduction

In the United States and Taiwan, diabetes was among the top 10 causes of death in 2005. There are approximately 21 million people with diabetes in the United States, representing 7% of the population (Center for Disease Control and Prevention, CDC 2005). This high rate of prevalence is also found in Taiwan. According to the Taiwan National Department of Health (2004), there are around 1.11 million diabetic patients in Taiwan, representing 4.91% of the population. People with diabetes are at higher risk for heart diseases, blindness, kidney failure, extremity amputations and other chronic conditions (American Diabetes Association (ADA), 2003). In addition, diabetes imposes a substantial cost burden to society and patients. Based on ADA (2003) statistics, healthcare spending in the United States in 2002 for people with diabetes is more than twice for people without diabetes. Similarly, according to the Bureau of National Health Insurance (NHI) Annual Statistic Information Service in 2002, diabetes accounts for 11.5% of overall healthcare spending in Taiwan. Reducing the health problems caused by diabetes through effective disease management can significantly improve the quality of life for diabetic people and reduce national expenditures for healthcare services.

Background

Diabetes patient education

According to the World Health Organization, the main goal of patient education regarding diabetes is to help diabetics and their families become 'active participants' in the management of their disease (as cited in Coates & Boore 1995). In other words, patients are expected to participate actively

in their diabetes education and the development of their self-management plans. Diabetes self-management requires patients to engage in the often complex self-regulation of their health behaviours. In fact, studies have demonstrated repeatedly that diabetes self-management is poorly explained or influenced by compliance-based approach to behaviour change (Anderson 1985, Glasgow & Anderson 1999, Glasgow & Eakin 1998, Lutfey & Wishner 1999, Anderson & Funnell 2000, Engelgau *et al.* 2000). Recent meta-analyses have found self-management interventions to have a positive short-term (six months or less) impact on diabetes-related health outcomes, specifically increasing diabetes-related knowledge and improving blood glucose monitoring, dietary habits and glycaemic control (Brown 1988, 1990, Norris *et al.* 2001, 2002, Barlow *et al.* 2002, Sarkisian *et al.* 2005).

Culturally tailored diabetes patient education

One characteristic of successful programmes is culturally tailoring them to the needs and aspirations of the population of interest. (D'Eramo-Melkus *et al.* 2004, Sarkisian *et al.* 2005). Culturally relevant healthcare is based on the importance of understanding patients' health experience within their unique social, cultural, familial, economic and environmental circumstances. Health beliefs and health behaviour are influenced by cultural and socioeconomic factors (Anderson *et al.* 1996, 1998, 2000, Sarkisian *et al.* 2005). Many Taiwanese patients with chronic illness (e.g. diabetes), for example, often seek their own healing methods (e.g. Chinese herbal medicine, acupuncture, folk prescription and supernatural healing), some of which may contradict the evidence-based treatment. Unfortunately, many of these patients develop acute renal failure or even incurable uremia because of the use of unknown sources of herbal regimens

(Yang *et al.* 2001). The relationship of culture to health beliefs and health behaviour is especially important in the treatment of diabetes, which usually involves changing patterns of eating, physical activity and other culturally embedded behaviours. If diabetes treatment recommendations are to be effective, they must be sensitive and relevant to the culture of the people who are expected to carry them out (Murphy *et al.* 1993; Anderson *et al.* 2000).

According to Wilkinson (1999), focus groups are a more 'naturalistic' method in that they draw on people's normal and everyday experiences. Because of their ability to capture the nuances of cultural perceptions and behaviour, focus groups have become the method of choice to understand culturally and tailor diabetes patient education programmes (Anderson *et al.* 1996,1998,2000, Sarkisian *et al.* 2005). In fact, the use of focus groups to tailor patient education programmes has been one factor associated with successful programmes (Edworthy 2000, Newman *et al.* 2001, Yang *et al.* 2001, Sarkisian *et al.* 2003).

Understanding patients' diabetes self-management

Although healthcare professionals can provide input into the self-management of diabetes such as symptom management, self-care techniques, social and emotional management, or other information necessary to make informed decisions, the patients must make these tactics work in the contexts of their own lives. In other words, patients need the ability to self-regulate their chronic conditions. Self-regulation has been defined as a person's ability to modify voluntarily one's physiological activity, behaviour and processes of consciousness through the processes of self-monitoring, self-evaluation and self-reinforcement (Massey & Pesut 1991). Data demonstrate that patients' ability to manage chronic disease depends on their level of self-regulation (Clark & Partridge 2002). Accordingly, self-regulation is an integral component of self-management (Price 1993, Clark & Partridge 2002, Gonder-Frederick *et al.* 2002, Petrie *et al.* 2003). Patients can develop their repertoires of strategies for managing disease through the use of self-regulation.

The importance of patients learning self-management through self-regulation has been recognized in the literature (Price 1993), but some of this research has focused on skills to manage symptoms. Studies about how patients self-manage their diabetes in terms of patients' perspectives have been scant. Therefore, the purpose of this study was to explore the lived experience of patients in Taiwan with self-management of type 2 diabetes. The specific aims were to: (1) explore experiences that the participants have in managing their diabetes; (2) explore the experience of how the participants

learn to manage their diabetes; and (3) explore what information and skills are required for a successful self-management of diabetes. These findings will contribute to better understanding of the experience of diabetes self-management so that innovative interventions can be developed from a patient-centred rather than disease-focused approach.

Methods

Design

In this study, focus groups were used to explore how patients with type 2 diabetes described self-management of their illness in the context of their own sociocultural environment.

Participants

Participants were recruited through purposive sampling from three teaching hospitals in two cities located in southern Taiwan, with assistance from the representative of the diabetes support group and diabetes health educators. For inclusion in the study, participants had to: (1) be at least 20 years of age; (2) be able to communicate verbally in Taiwanese or Mandarin Chinese; (3) have had diabetes for five or more years; and (4) provide consent to participate. Participants were given \$10 honorarium for their participation at the completion of the focus group session. The focus group sessions were held in hospital conference rooms. Five focus groups ranged in size from six to ten people in each. The 41 total participants included 19 women and 22 men who were between 42–81 years of age (mean = 61.37, SD = 9.77). All participants were married. Seven had completed a baccalaureate degree, thirty had completed high school and four had elementary school or less education. Time since diagnosis averaged 9.19 years (SD = 6.06).

Data collection procedures

The study was approved by the institutional review board at a major Midwestern United States university. Permission to conduct the study was obtained from administrators at three teaching hospitals located in southern Taiwan. The primary investigator moderated all five focus groups. At the beginning of each focus group, the moderator introduced herself and another research team member who took field notes and described the planned focus group session. Moreover, to encourage active discussion of all focus group members, participants were asked to openly discuss their experiences and provide candid responses, even if they differed from the responses of other participants. All of the sessions, lasting from

90–120 minutes, were recorded by two microcassette tape recorders to ensure clarity and accuracy of transcriptions.

Focus group protocol

An interview guide with the focus group questions was developed. To test the relevance and clarity of the interview guide, it was distributed for review and critique to four people with type 2 diabetes, three diabetes specialist nurses and one expert who had experience in working with focus groups. The interview guide was then revised based on the reviewers' recommendations. The three major research questions were based on the three aims of the study as follows: (1) what experiences do the participants have in managing their diabetes? (2) what are the experiences that the participants have learnt to manage their diabetes? (3) what do participants describe as information and skills required to manage their diabetes successfully.

During the focus group sessions, questions were logically posed from the general to the specific, but still allowed for flexibility for clarification and probing (Cote-Arsenault & Morrison-Beedy 1999, Krueger & Casey 2000). Probing questions help participants more clearly and specifically describe their experiences. Examples of probing questions were 'What is the impact of diabetes on your life?' 'What is the biggest problem you have encountered in trying to manage your diabetes and how do you solve or cope with these problems?' 'What types of information or skills do you think would be most useful for you and others for managing the diabetes?' 'What are important lessons (they may be positive or negative) that you have learned in managing your diabetes?' 'How did you learn these self-management strategies?' 'Of all the strategies we discussed, which ones do you think are most important to achieve satisfactory diabetes self-management?' 'Is there anything that we missed about what information (e.g. knowledge, resources) or skills should be identified to achieve successful diabetes self-management?'

Data analysis

The analysis was the collective experience of the 41 participants. To obtain an accurate interpretation of audiotapes, Krueger (1997) suggests that data analysis should be conducted by the researchers attending the group discussions. Using the methods outlined by Colaizzi (1978), data were analysed by the primary investigator, who was also the moderator of the focus groups, as well as by the research team member who observed the focus groups; all of the transcripts were first read and then re-read to obtain a sense of the content. Next, significant statements and phrases relating to the phenomenon

under study were extracted as units of analyses. Although the focus group interview questions addressed elements of patients' self-management of their illness, transcripts were read with no preconceived expectations of what themes might develop. Phrases, units of analyses, were grouped according to their meaning. As categories became apparent, statements were grouped under emerging themes. Each unit of analysis was consistent with a theme that emerged. These themes addressed the participants' experiences of self-management but also included responses and themes that were broader and incorporated participants' comments about having the illness and the social context that influenced their self-management.

Findings

Participants in the five focus groups described their experiences with self-management of diabetes. The analysis of the data resulted in the identification of three major themes, each with several related subthemes.

Theme 1: Impact of the illness

People described significant impacts on their life once they were diagnosed with diabetes. Three subthemes emerged from the participants' descriptions about the impact of diabetes on their life as follows.

Subtheme 1a: Facing the predicament of stigmatization

Participants described the stigma associated with having diabetes. One participant noted: 'Since diabetes is an illness of the rich, it was traditionally a taboo to talk about it. It means that wealthy people are infected with a disease. ... If you are a diabetic patient, other people are afraid that you will infect them. Another participant reported: 'Once I visited relatives in Canada, every time when we ate, I was given extra tableware and the parents told their children that I had diabetes'. The other participant who had chosen alternative medicines in an effort to be cured said in an angry tone 'You health professionals should do something ... should educate people that diabetes is not infectious disease ... it will not contaminate others ... diabetic patients are not different from other people ...' He emphasized 'We are not inferior people'.

These statements are examples of participants' experiences of stigma. They explained that diabetes is an illness for the rich people and it is a self-inflicting disease resulting from over-indulgence with food. Participants reported that many people consider their diabetes as an infectious disease and make them feel shameful. The participant's description of the need to be normal and distress about being stigmatized occurred in these groups.

Subtheme 1b: Concern with inheritance and consequences of diabetes

Participants made the following types of statements about the impact of inherited disease. One participant stated: 'It really strikes me to think of having this disease at such a young age ... but I am really worried about possibly fatal complications. My mom has been dead of it and my time may soon come, so I have started to think about death a lot'. Another said: 'My family has a history of the disease, too. My mom had diabetes. She died when she was still young because knowledge about diabetes at that time was poor'.

Participant's description indicated their concerns about the consequences of diabetes, especially for their family. They also described the fear of death from the illness. These statements support the theme of concern with the inheritance and consequences of diabetes.

Subtheme 1c: Seeking alternative therapies for hope

Participants described seeking alternative treatments (such as Chinese medicine, herbs and the roots/stems/leaves of plants or even unusual medical devices) other than conventional approaches. One participant said: 'A salesman once persuaded me to buy a machine that looked like a spaceship. The price was approximately NTD 1 000 000 (i.e. US\$29 000) high. He said that all I needed to do was lie down in the capsule for 40 minutes and no medicine was needed at all. The light from the machine would cure my illness'. Another said: 'A lot of TV commercials boasted that diabetic patients could fully recover by taking it. In fact, it was not true. There has not yet been a successful case of recovery. Many patients spend a lot of money in alternative therapy, but things just get worse'.

These examples are indicative of participants' attempts to use alternative interventions to cure their diabetes. These efforts resulted in lack of response to the alternative treatment, expenses associated with the treatment, stopping conventional treatment to use the alternative and efforts by other people to sell products and advocate for non-conventional interventions.

Theme 2: Self-regulation process

Participants learned to manage their illness through the process of self-regulation. Four subthemes emerged from the participants' descriptions that explain how they learned self-management strategies as follows.

Subtheme 2a: Struggling for diet control

Participants described learning to manage their diabetes by diet control. One participant said: 'I like noodles very much,

but I can only have rice due to the disease. It is killing me. It seems that control over blood sugar is impossible ...' Another participant said: 'I am fat and enjoy eating, but now that I have diabetes, I have to control everything I eat. I usually eat three bowls of rice at every meal, but these days what I eat is digested as sugar. You can't imagine how much I want to have a bite of any food'.

These examples are indicative of the experiences that the participants struggle with diet control. Participants explained that, although they were aware of the importance of diet control for preventing diabetic complications, how difficult it was to change their eating patterns.

Subtheme 2b: Identifying body responses

Participants described leaning to control their blood sugar. One participant said: 'If I know that I am going to a social dinner, I am sure that I will eat more than usual. When I get home and measure my blood sugar, it really rockets up to 180, 190, or even 200!' Another noted: 'If I eat too salty or sweet food, I get thirsty with frequent urination and my waist is sore. I know that this is an alarming sign of the body and certain food is not allowed. Later, I listen to my body.' A participant said 'Sometimes I bring home negative emotions and feel tired. If I measure my blood sugar at this moment, the figures increase, so I try to calm down and relax little by little.'

These examples are indicative of participants' learning to control their blood glucose through recognizing the cause-and-effect relationships between life events (e.g. diet change, stress) and body response (e.g. thirsty, increased blood sugar level). Participants learned strategies for managing their diabetes as they experienced body cues and measured their blood glucose.

Subtheme 2c: Adjusting to psychological barriers

Participants described the adjustment process of facing diabetes. A participant said: 'As time goes by, you no longer feel anything about it. If people ask me about diabetes, I just tell them that it is no big deal. If people ask me now, I am comfortable with it'. Another said: 'Originally, I did not want to let others know that I have diabetes ... My wife told me that if they knew about it, they would probably share their experiences with me. It made sense to me and I started to open my mind. It was exactly like what my wife said'.

These statements supported how difficult it was for the participants to overcome their psychological barriers. Participants explained that they tend to avoid revealing their diabetes because of the perceived stigmatization from people's attitude towards diabetes. They took a long time to adjust their own attitude and gradually realize that it is okay to let others know of their disease.

Subtheme 2d: Developing strategies for dealing with diabetes
Participants reported how they get the tips to integrate the diabetes regimens into their daily life. One participant stated: 'At first, I always forgot to take medicine and then, I prepared a small bag. There I put three pills. I took two already and there the last one was for dinner'. Another described: 'When people get together, I pretend to eat the junk food and leave the table right away. Actually, I go to the bathroom to throw it up. Well, it is just for my pure pleasure and I need not refuse other people'.

These examples supported the theme that participants develop their unique tips for managing the disease from self-observation and self-evaluation from which participants found out the strategies working best for them. These tips included how to take medicine, perform exercises, control diet and develop special social skills. From the learned strategies and skills of illness management, participants gradually integrated the diabetes regimen into their daily life.

Theme 3: Transformation process

Through the process of self-regulation, participants realized that diabetes can be controlled and reformed their attitudes towards diabetes. Three subthemes emerged from the participants' descriptions about the transformation process as follows.

Subtheme 3a: Resuming conventional treatment

Participants described resuming conventional treatment as important for diabetes management. One participant said: 'I think that diabetic patients like us should consult all the resources including a doctor, a dietitian and a nurse specialist as well as a psychological counselor when necessary'. Another stressed the importance of adherence to treatment plan: 'Don't treat yourself as a poor diabetic patient. I strictly follow the three major principles, that is, diet, exercise and medication everyday'.

Many participants who tried alternative therapies found that it is useless attempting to cure their diabetes using alternative therapies. This recognition allows participants to make recommendations about resuming conventional treatment including interacting with health professionals and adherence to diabetic regimen.

Subtheme 3b: Support from families and fellow patients

Study participants stated that family and fellow patients are their resources to manage the diabetes. One participant said: 'I remember to inject insulin every morning but when things get busy at night, I forget to do it. Fortunately, my wife, Mom or grand daughter remind me from time to time'. Another

stated his support from fellow patients. He said: 'Most members of the fellow-patient groups influence one another. We share tips to stay on the right track and to remain happy and healthy'.

These examples are indicative of support from families and fellow patients. These supports help them more effectively manage their diabetes regimen and achieve a balanced life.

Subtheme 3c: Learning to live with the disease

Participants described how they live with this lifelong disease. One participant whose mother died of diabetes during her young stage had pessimistic belief towards diabetes. She said 'The medical knowledge was insufficient in my mother's era, people thought that it was impossible trying to control the diabetes...but, I myself experienced that as long as I follow diabetic educator's instructions, my blood glucose was controlled very well. Now, I often shared with other patients in the diabetic support group that diabetes is nothing to be afraid of ... it can be controlled.' Another stressed: 'Consider it's part of your life! I am a housewife, so I decide what the family eats and control the intake of fish or meat. This is self-management! I always integrate diet and exercise into my daily life'. Some participants also described their attitudes towards diabetes. One said: 'Don't be so uptight. I have already had this disease and nothing can be worse, so why not live your life happily? Try to think positively and have a nice day'!

These participants' statements support the theme of learning to live with the disease. This transformation came about from their realization that accepting the disease as part of their life and being optimistic was the best strategy for managing the disease.

Conclusion and discussion

The findings of this study suggest that patients go through three major trajectories as the following during the process of diabetes self-management which reflected directly to the specific aims of this study.

Impact of illness

Findings from this study demonstrated that individuals with diabetes experience significant impacts on their life when they were diagnosed with diabetes. Participants reported that they often suffered the plight of stigmatization. This finding was also found in the study by Shiu *et al.* (2003) in Hong Kong. Because of social stigmatization of diabetes, in the initial stage, study participants described being limited to their own world or family and not seeking resources from outside.

Besides enduring the embarrassing stigmatization, they were afraid of diabetic complications and worried that this inherited disease would pass on to their children. This kind of impact of illness supports Corbin and Straus (1988) notion that emotional management is an important task for managing chronic illness. In other words, patients with diabetes have not only to manage physiological needs, but also deal with the emotional problems.

With this kind of pressure of stigmatization and concern about inheritance of diabetes, patients were experimenting with alternative treatments in an effort to be cured. This finding demonstrated that self-management of diabetes by Taiwanese patients reflects their culture. The predominant Chinese culture considers traditional Chinese medicine as the primary treatment of a disease, while western medicine treats symptoms instead of healing. It was not surprising, therefore, that diabetic patients sought out alternative treatments, especially traditional Chinese medicine, hoping to cure their disease. Despite adopting alternatives being a common phenomenon, patients usually do not talk about any alternative treatments in traditional western settings because they are afraid that healthcare providers may disagree with them. However, self-management strategies that use alternative regimens may reflect patients' sociocultural contexts. Healthcare providers need to respect and encourage the discussion of alternative treatments, recognizing the patient as an active participant in managing their diabetes. However, without guidance, information about alternative therapies from laypersons or the media may become harmful or distracting rather than helpful (Edworthy 2000). Thus, patients' experiences of seeking alternative treatment for disease management deserve additional research.

Self-regulation process

Data from the five focus groups indicated that patients learned the strategies for managing their disease from a series of self-regulating processes including biobehavioural and psychological adjustments. For example, through 'identifying body response,' participants learned the relationships among blood sugar level and diet control and emotional relaxation. By recognizing the pattern of their own biopsychosocial responses to diabetes, they gradually formulated a diabetes self-management plan that worked for them. This finding is consistent with Price's (1993) study in which participants modified their prescribed management regimen based on bodily responses or personal schedules; it also reflects that self-regulation is an essential component of self-management as described in the literature (Clark *et al.* 1992, Price 1993, Gonder-Frederick *et al.* 2002). Through

self-regulation, patients found ways to integrate the recommended regimens into their daily lives. This kind of self-management strategy through the learning of self-regulation reflects that patients themselves are the experts about their own illness. As Paterson and Thorne (2000) stated, healthcare professionals often use physiological data to determine the efficacy of disease management, but people interpret such data in terms of what they know to be their usual patterns of body response and what they believe is necessary to achieve well-being.

Diabetes is an incurable chronic disease, thus, its management process must be oriented towards care, not cure (Price 1993). It is important for diabetic patients to develop their own repertoire of coping strategies for their long-standing disease through the use of self-regulation. Health educators may assist patients to learn the skills of self-regulation by self-monitoring, evaluating its effects and trying out the new behaviours (Clark *et al.* 1992).

Transformation process

Diabetes management is a lifelong lesson. For diabetic patients, the self-management process is a total life experience, not limited to tasks associated with physiological needs (Clark *et al.* 1992). In a unique sociocultural context, Taiwanese patients diagnosed with diabetes bore the plight of stigmatization and were haunted by this inherited disease. However, when recognizing the nature of diabetes, which cannot be cured but can be controlled through the experimental learning of self-regulation, participants reformed their beliefs towards this long-lasting disease. An initial transformation occurred once participants discovered that they themselves know best what worked for them physically and psychologically from which participants found ways to live with their disease.

Through the transformation process, participants realized that accepting the disease as part of their life was the best strategy for managing the disease. Additionally, they realized that they have to collaborate with health professionals and get support from families and fellow patients as well as actively take charge of their illness management for preventing complications, maintaining optimum health status and minimizing the intrusion of the disease into their preferred life styles. This transformation demonstrates that participants were gradually able to apply the knowledge and information they learned to multiple new situations through self-regulation experience. This study's findings reflect the notion by Tobin *et al.* (1986) that self-management processes involve all cognitive, physiological, behavioural and social activities associated with managing chronic illness.

Based on the themes that emerged from this study, it has important implications for healthcare providers to consider individuals' sociocultural backgrounds in which they make choices about their treatment and manage their illness. A better understanding about this issue may help health professionals develop an effective self-management programme that is patient-centred rather than disease-focused.

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Contributions

Study design: CCL; data analysis: CCL, BOL and manuscript preparation: CCL, RMA, BMH.

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