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“Diabetes? I can live with it”

**A Qualitative Evaluation of a
Diabetes Self-Management Programme**

**A thesis presented in partial fulfilment of the requirements for the degree of
Master of Arts in Psychology
at Massey University, Palmerston North,
New Zealand.**

Daniela Andrae

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Abstract

Self-management programmes provide one form of education for people with diabetes. Evaluations of these programmes allow for a better understanding in regard to their impact and whether outcomes are met. Very little research has used qualitative methods to capture participants' experiences of these programmes and their perception of psychological outcomes. This is the first qualitative evaluation of the Type 2 Diabetes Self-Management Programme in Whangarei. It has adopted an interpretative-phenomenological approach to explore participants' experiences of the programme and participants' perceptions in regard to their self-efficacy and quality of life after attending a course. A sample of 7 participants with diabetes provided data via interviews 4 weeks and 3 months after attending the course. The themes that emerged from the initial interview were separated into three evaluation components. In "6 weeks sounded very long but it was worth the time", participants discussed enrolment, benefits of the course and suggestions for future participants. In "I know what I need to do and I'm confident to do it", participants linked the gained knowledge from the course to improvements in their self-efficacy regarding self-management behaviours, education and control of own life. In "Life is good, diabetes is just another thing to handle", participants reflected on the impact of living with diabetes and changes to their life. An overarching theme of settling into a comfortable routine emerged from the follow-up interview. Participants reflected positively on their course and research participation. The programme was perceived to be beneficial to participants, impacting positively on increasing knowledge, self-efficacy development, behaviour changes and quality of life. The participants maintained these benefits in the short-term. These results are discussed in terms of the need for further research to evaluate if benefits are maintained in the long-term, referral process to the programme, decision-making process in regard to enrolment and impact of a support person attending the programme. Practice implications for the programme are discussed in regard to incorporating a follow-up phone call to participants after they attended a course and offering follow-up sessions with the latest information on diabetes care.

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Chapter 1 Diabetes

From prevalence to self-management/education

1.1. Background of the study

Diabetes is a chronic disease that is both irreversible and progressive. The World Health Organization is predicting a 71.5% increase in the incidence of diabetes in New Zealand between 2000 and 2030 (WHO, 2007). Diabetes was identified as a major health concern by the New Zealand Ministry of Health and included as one of their 13 health priorities in 2001 (Ministry of Health (MoH), 2003).

In Northland diabetes has also been identified as a major health need and the recently implemented diabetes strategy (STAND) reflects this concern. STAND consists of seven areas of action and three important aspects of these are a) to support enhanced primary care, including chronic care management, b) review diabetes services and c) regular audits of the patients' experience (Northland District Health Board (NDHB), 2006a).

1.2. Definition of diabetes

Diabetes mellitus is as a group of metabolic diseases/disorders. These diseases are multiple in aetiology, characterised by chronic hyperglycaemia caused by defects in insulin secretion, insulin action or both (American Diabetes Association, 2006; WHO, 1999). Chronic hyperglycaemia can lead to metabolic disturbances and is associated with the risk of long-term complications to various organs (NDHB, 2006a).

1.2.1. Types of diabetes

There are three main forms of diabetes mellitus. Their current classification into Type 1, Type 2 and gestational diabetes is fairly recent (circa 1990s), with a focus on aetiology of the disease rather than its treatment (Slama, 2003).

Type 1 Diabetes is an autoimmune disease, generally characterised by beta-cell destruction in the pancreas (about 90% of Type 1 cases), which leads to absolute deficiency in insulin secretion. Onset is usually rapid and diagnosis generally occurs

between childhood and young adulthood (<30). There are a number of subtypes and it is noteworthy that one form of Type 1 diabetes occurs in adults >40.

Type 2 Diabetes is the most common form and is classified as a heterogeneous syndrome due to the interaction of environmental factors (especially obesity, sedentary lifestyle and physical inactivity) and genetic factors. The combination leads to beta-cell failure and different combinations of insulin resistance. Onset is slower and people with Type 2 diabetes are often asymptomatic. People diagnosed are generally in middle or late adulthood (>40), with a peak onset between 60-70. Recent years have seen an increase in the diagnosis of children and adolescents with Type 2 diabetes, particularly in combination with obesity. Diagnosis is often made during routine medical checks, during hospital admission for other conditions or when symptoms such as tiredness, lethargy and/or complications occur (Katsilambros & Tentolouris, 2003; NDHB, 2006a; Ross & Gadsby, 2003).

Some women develop **gestational diabetes** during the second or third trimester of their pregnancy. Gestational diabetes occurs in 2-5% of all pregnancies. Pregnancy hormones resulting in a shortage of insulin or insulin resistance cause this form of diabetes. It is often asymptomatic and women may not show any symptoms at all. (Auckland Region Diabetes Nurse Specialist Group, 2001).

1.2.2. Diagnosis of diabetes

The World Health Organization (2006) recommends the use of venous plasma glucose as the standard measure for diagnosis of diabetes. The current criteria for the diagnosis of diabetes in New Zealand (New Zealand Guidelines Group, 2003, p.2) are as follows:

- Two fasting venous plasma glucose results ≥ 7.0 mmol/L on two different days
- or**
- A random venous plasma glucose result ≥ 11.0 mmol/L on two different days

1.2.3. Prevalence of diabetes

Prevalence of diabetes in New Zealand was estimated to be around 86,000 in 1996 (MoH, 2002), which increased to 115,000 diagnosed people with diabetes. It is assumed that a further 40,000-60,000 cases remained undiagnosed in 2000 (Health

Funding Authority (HFA), 2000). In *Diabetes 2000* it is predicted that by 2021 the prevalence of diabetes will increase by 97%, 117% and 47% in Māori, Pacific Island and European populations respectively (HFA, 2000). An estimated 5,644 people in Northland have been diagnosed with diabetes. It is assumed that a further third or even half of this number remain currently undiagnosed (NDHB, 2006a).

Type 2 diabetes accounts for around 90% of the cases worldwide and could affect “5-7% of the world’s population” (Katsilambros & Tentolouris, 2003). The New Zealand statistics reflect this worldwide trend, seeing that of all diagnosed cases “95% of Māori people have Type 2 diabetes, and 89% of European” (HFA, 2000). In 2000 the predicted total number of people with Type 2 diabetes in Northland was 4659 (HFA, 2000).

1.2.4. Predicted causes for increase in diabetes

Predicted causes for the increase in diabetes, particularly Type 2 diabetes, over the next decade are demographic structures (population size 30%, age structure 20%, ethnic mix 11%, secular mortality trend 4%, health care 5%), which are not possible to modify, while increase in obesity (30%) would account for the remaining third. The major aim is to slow down the rate of obesity by improving nutrition and increasing physical activity within the population (MoH, 2002).

1.2.5. Risk factors for Type 1 and Type 2 diabetes

For both types, a family history of diabetes increases the risk. Type 1 diabetes is more common in people of European descent and this appears to be a worldwide trend (HFA, 2000, American Diabetes Association, 2005). Type 2 diabetes is more common in people who are overweight, have high blood pressure and/or raised cholesterol levels. For women, giving birth to babies that weigh more than 4 kg and/or having previously been diagnosed with gestational diabetes can also increase the risk for later development of Type 2 (American Diabetes Association, 2005; Diabetes New Zealand, 2005).

1.2.6. Long-term complications of diabetes

Even though people with Type 2 diabetes are sometimes informed that they have a milder version of diabetes compared to Type 1, they are as likely to develop serious complications (NDHB, 2006). The most common long-term complications in New

Zealand in regard to diabetes are diabetic foot disease, heart attack, blindness and renal failure (HFA, 2000). This trend is mirrored in Northland, with a 20% prevalence rate of retinopathy in the total diabetes population in 2004/05, which was higher than rates for other regions (NDHB, 2006a).

Diabetes 2000 statistics (HFA, 2000) indicate that Māori and Pacific Island populations are more likely to develop long-term complications compared to the European population. The Ministry of Health (2005) points out that for Māori and Pacific Island populations the complications are also more severe.

Particularly, good control of blood glucose levels (within a normal range of 4-8 mmol/l), blood pressure and cholesterol have been linked to significantly reducing the risk of developing these long-term complications that could otherwise develop 8-10 years after onset of diabetes (American Diabetes Association, 2005; Diabetes New Zealand, 2005). Results from the United Kingdom Prospective Diabetes Study (UKPDS, 1998a), the largest clinical study in regard to Type 2 diabetes, highlighted the importance of glycaemic control. This trial showed that well controlled blood glucose levels reduce the risk of developing microvascular complications. The risk of developing retinopathy was reduced by a third and early kidney damage by a quarter.

In Northland around a third of all people with diabetes have blood glucose levels that are poorly controlled (NDHB, 2006). Over a four-year period admission to hospital (2001-2005) not only increased by a factor of 3.3 but the average number of days people stayed in hospital also rose from 3.95 to 4.84. In the year 2003/04 1,439 people were hospitalised with a primary or secondary diagnosis of diabetes. Out of these, 1,173 people had diabetes as a secondary diagnosis, i.e. they were admitted for diabetes-related complications of the circulatory system and other problems (NDHB, 2005).

1.2.7. Mortality and morbidity associated with diabetes

In New Zealand the average duration of diagnosed diabetes (from diagnosis to mortality) is lowest for Māori (around 18 years) and longest for Europeans (around 23 years). This, even though Ministry of Health (2002a) models show that the average age at diagnosis for Māori and Pacific Island people is approximately 47-48, compared to 54 for Europeans. This national trend is reflected in Northland, with the highest

incidence rate of new cases being diagnosed around age 45 for Māori compared to age 57 for Europeans (NDHB, 2006b)

Ministry of Health models further show that about 5% of all deaths in New Zealand in 1999 were attributable to diabetes (2003). While this is the national average, “for Māori the proportion of deaths attributable to diagnosed diabetes is 19.5%” (MoH, 2002a, p.14) and 3.5% for Europeans. 43% of deaths of people with diabetes can be directly linked to diabetes-related causes (MoH, 2002b). Again, this differs depending on ethnicity; 36% of Europeans can expect to die from diabetes-related causes compared to 63% of Māori (MoH, 2002c). This trend is similar for Northland, with Māori on average dying at a younger age (with a peak occurrence at age 65) and at a higher rate compared to non-Māori (NDHB, 2006b).

Results from the United Kingdom Prospective Diabetes Study (UKPDS, 1998a), showed that a 1% reduction in haemoglobin A1c (HbA1c, an indicator of blood glucose control over the past three months) lead to a 21% reduction in the risk of diabetes-related deaths. Results also indicated that good blood pressure control could reduce diabetes-related death by around 30%.

In response to the growing diagnosis, particularly of Type 2 diabetes, in New Zealand Diabetes 2000 (HFA, 2000) and the New Zealand Health Strategy (MoH, 2003) call for the development of effective diabetes care by a collaborative and multidisciplinary team. A combination of support and education by primary and secondary health providers is seen as an important step in helping people to manage their diabetes effectively, to reduce the onset of complications and the demand on health services (NDHB, 2006).

1.3. Self-Management

Self-management is the cornerstone to care/treatment; it is therefore crucial that the person with diabetes is well informed and active in his or her own care (Funnell, 2007). Management of Type 2 diabetes can be through insulin injections, oral medication and often (at least initially) with Type 2 through lifestyle changes (especially diet and physical activity). However, changing lifestyles is a struggle for most people and adhering to the changes can be behaviourally and emotionally challenging. Not only is

there the adjustment of living daily with this chronic disease but there can also be fears and concerns in regard to developing long-term complications.

The World Health Organisation (2004) in its Global Health Strategy recommends that member states recognise the “heavy and growing burden of non-communicable disease” (p.1) and address specific strategies in regard to physical activity and diet.

Self-management is an important aspect of living with diabetes, as “people with diabetes provide about 95% of their own care” (Krichbaum, Aarestaed & Bueth, 2003, p.654). Combined with this has also been the realisation that lifestyle changes can improve the condition (i.e. being able to reduce medications) or slow deterioration and prevent the onset of long-term complications (Lorig et al., 1996).

1.3.1. Health sector attitudes towards self-management

Educating people with diabetes and their families is a key component of diabetes management and treatment programmes (Krentz & Bailey, 2005). The 1980s saw the foundation of associations in regard to diabetes education in America and Europe. Their aim has been to develop education programmes, define standards of care and outcome evaluations (Golay, Bloise & Maldonato, 2003).

Within the health sector a shift has occurred away from the medical model to a patient-centred pathway. While the medical model is sufficient when it comes to dealing with acute, particularly infectious diseases it is not sufficient when trying to deal with the complex aspects of chronic illnesses. Chronic illnesses, like Type 2 diabetes have multiple determinants and social, behavioural, economic and psychological factors affect the course of the disease.

This shift is particularly useful in diabetes education where the person with diabetes, and not the health professional, is more involved in decision-making, goal setting and management (Browning & Thomas, 2005; Lyons & Chamberlain, 2006). According to the NDHB (2006) an important aim of the patient-centred pathway is to “support the individual with diabetes to make informed decisions about their care” (p.43) and to work together in an equal relationship as co-partners when developing care plans.

1.4. Stages of diabetes education

The **initial stage** is at diagnosis and the focus of education should be on defining diabetes, its effects on the person's life and treatment options. During the **second stage** more in-depth information about diabetes is provided to the person with diabetes and support people. At this stage a diabetes self-management plan is developed between the person with diabetes and a health care provider. Ideally this planning would involve different members of the diabetes health care team and representatives of the person's social network. The **third stage** allows for continuing education and care (Auckland Region Diabetes Nurse Specialist Group, 2001; Krentz & Bailey, 2005).

The Diabetes Care Pathway (NDHB, 2006) highlights the different stages of diabetes education in Northland and is shown in Figure 1.

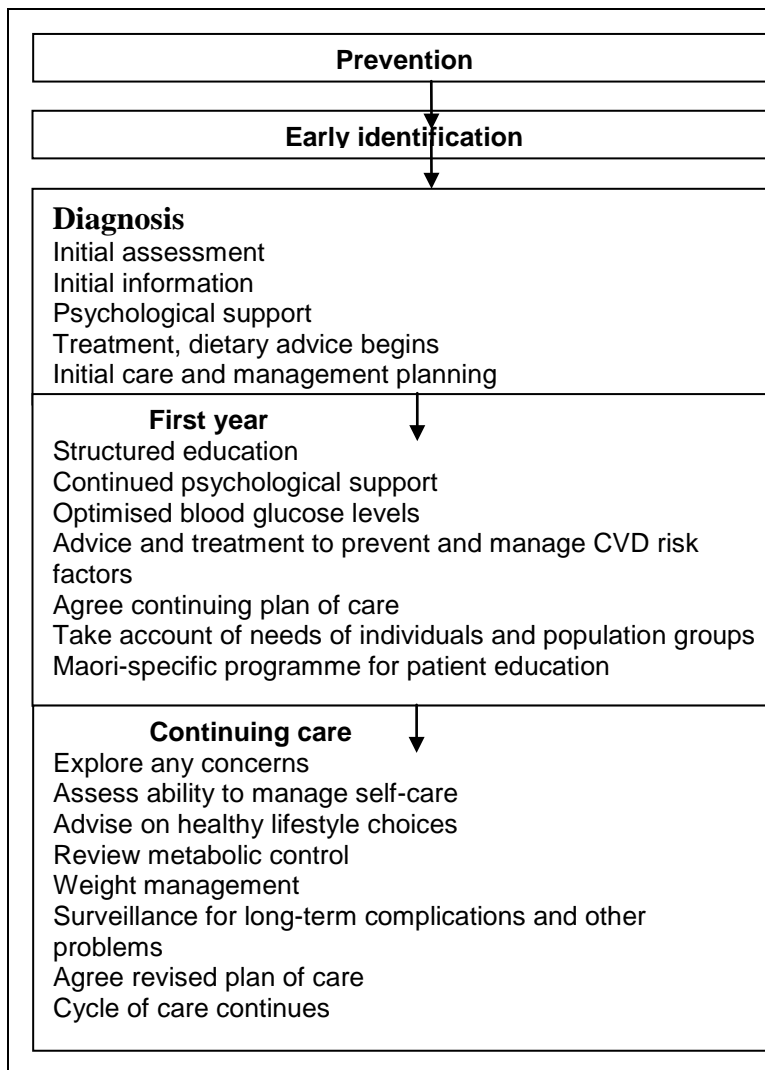


Figure 1. The diabetes care pathway (NDHB, 2006).

1.4.1. Focus and aims of diabetes education programmes

The International Diabetes Federation (IDF, 2003) states that the aim of diabetes education “is to empower people with diabetes to make effective self-management decision and use the health care system as a resource when necessary” (p.3). Diabetes education should be a “collaborative process in which people with diabetes gain the knowledge and skills needed to modify behavior and successfully self-manage the disease and its related conditions” (American Association of Diabetes Educators (AADE), 2007).

Corbin and Strauss (1988) point out that education programmes should focus on three tasks. These are the medical management of the illness, maintaining meaningful life roles and dealing with the emotional effects of having a chronic illness. According to Lorig et al. (1996) education programmes should also focus on the concept “of living with and dying with (rather than dying from) chronic disease” (p.2). Effective programmes need to identify and reduce barriers in regard to treatment and lifestyle changes as an important aspect of education (Morewitz, 2006).

Rutten (2005) believes that an important goal of programmes for people with diabetes is to “improve their individual self-efficacy and, accordingly their self-management abilities” (p.52). Therefore programmes need to focus on providing general knowledge about diabetes, medication, lifestyle changes and monitoring of blood glucose levels (ibid).

1.4.2. International guidelines for education programmes

Guidelines for content by the International Diabetes Federation (IDF, 2003) and the AADE (2005) for education programmes are shown in Figure 2.

<ul style="list-style-type: none"> • Healthy eating/nutrition • Exercise and activity • Monitoring and use of results • Medications 	<ul style="list-style-type: none"> • Problem solving • Healthy coping/stress/psychological adjustment • Reducing risks/complications
---	---

Figure 2: Guidelines for content for education programmes (IDF, 2003; AADE, 2005).

The IDF also adds a diabetes overview, family involvement/social support and use of health care systems to their content list.

1.4.3. Guidelines by the Northland District Health Board

The goals of patient education programmes by the Northland District Health Board reflect the international guidelines and are shown below in Figure 3.

- come to terms with diabetes and understand that it is a lifelong condition
- know the basics of the condition and potential complications
- understand the importance of controlling blood glucose levels, blood pressure and other risk factors and how these are achieved
- understand the importance of regular clinic attendances, the need for good foot care, eye checks and other areas where complications can be prevented or their onset delayed
- understand the need for healthy eating patterns and exercise, and the ways in which lifestyle can be modified to maximise wellbeing
- have the skills to manage insulin, injection techniques and hypoglycaemia
- understand the effect of illness and what action to take when they are ill
- understand the services, who does what, points of contact for advice and support especially out of hours

Figure 3. Goals of patient education programmes (NDHB, 2006).

1.5. Group versus individual education

Teaching individuals may be ideal for some people, seeing information can be applied specifically to the needs of each person. Golay et al. (2003) recommend it especially during the initial diagnosis stage, when basic information is given. There are a number of limitations to the individual approach, including time constraints, availability of staff/resources and higher costs (Tang, Funnel & Anderson, 2006).

Weinger (2003, p.86) points out “human beings are social creatures”. People with diabetes often feel isolated in their experience, seeing it is an invisible disease. Group education plays an important role in allowing people with diabetes to get together and share their problems, fears and hopes. Through sharing of experiences and ideas members can learn and benefit from each other and develop new self-management strategies. Group sessions appear to foster greater interaction, emotional support, and acceptance of information and enable the use of different educational strategies, including modelling and interactive learning (Zrebiec, 2003; Tang et al., 2006). Group education is also more cost effective and efficient (Mensing & Norris, 2003). Finally, Weinger (2003) points out that this type of teaching helps to disseminate the latest

information faster to people with diabetes, seeing each person with diabetes “is likely to teach another patient” (p.86).

Disadvantages of groups include the issue surrounding confidentiality and that the individual receives less time and attention from the health professionals. While for some people attending group sessions might feel ‘safer’, others might feel that they are ‘lost in the crowd’ (Golay et al., 2003; Zrebiec, 2003).

A systematic review of 72 studies in regard to the effectiveness of individual vs. group self-management programmes for Type 2 diabetes has shown that group education appeared to be slightly more effective in regard to changes in lifestyle. Both types of education have positive effects on dietary compliance and self-care behaviours, particularly when they focused on participation and collaboration with the participants. The importance of reinforcement and follow-ups over time was stressed in regard to effective self-management programmes (Norris, Engelgau & Narayan, 2001).

1.5.1. Diabetes Self-Management programme in Whangarei

One example of a group education course is the Diabetes Self-Management Programme in Whangarei. This is a collaborative project between staff at Manaia Health Primary Health Organisation (PHO) and the Whangarei Diabetes Services (Diabetes Lifestyle Centre). It was designed to help people manage the day-to-day challenges of Type 2 diabetes and to better understand their condition. It aims to help people learn skills in regard to diabetes care and to gain confidence in managing their condition (Manaia Health PHO & Northland Health Ltd, 2007a).

In 2007 Manaia Health PHO started to promote, organise and run the diabetes self-management programme. In general the plan is to run courses with a maximum of 12 people (with diabetes and their support person), as this good group size is assumed to encourage interaction and sharing of experiences. Three diabetes self-management courses were offered in 2007.

Three staff members lead through the sessions, a diabetes resource nurse, a dietician and a psychologist. Guest speakers include a podiatrist and a diabetes nurse specialist to discuss podiatry and physical activity respectively.

The course is delivered at the local PHO, which is centrally located. Seating is arranged so that all participants are able to see each other and equipment used during the sessions. The July/August course was a morning course, while the November/December course ran in the afternoon; to a certain extent session time changes depend on participants' preferences. On arrival at the first session, each participant is personally welcomed by one of the three leaders and a folder with relevant information and a nametag is distributed. Coffee, tea and water are provided throughout the session and during the break light snacks (that are healthy choices for people with diabetes) are provided.

An important goal during the sessions is to create an environment in which participants not only learn from the course facilitators but also “share and gain wisdom, support and motivation from others with the same condition” (Manaia Health PHO & Northland Health Ltd, 2007a). Confidentiality of content of the sessions is also assured to the participants in session one and reasons for this are discussed.

Programme Design

This Diabetes Self-Management Programme is a free course comprising of six weekly sessions. Five of these sessions last approximately 2 ½ hours, while one session (the supermarket tour) lasts for around 1½ hours. A variety of techniques are used during the course: whiteboards, hand outs, overhead projector, quick quizzes, large and small group discussions, PowerPoint presentations, goal setting and a supermarket tour.

A broad range of topics is covered during the programme and is listed in Figure 4.

<p>Session 1: What is diabetes? Emotional and self management issues around dealing with diabetes</p>	<p>Session 2: Healthy eating Physical activity</p>
<p>Session 3: Carbohydrate containing foods Blood glucose monitoring</p>	<p>Session 4: Long-term complications Foot care Medications</p>
<p>Session 5: Supermarket Tour</p>	<p>Session 6: Communicating with health professionals Emotional issues Support groups</p>

Figure 4: Topics of the diabetes self-management programme (Manaia Health PHO Ltd, 2007e)

During each session participants have the option to take home handouts and brochures in regard to information covered in the specific session. These are not distributed to the participants but rather participants are encouraged during the breaks to choose ones that are of particular interest to them.

Week 1-4: Contracting (goal setting)

A goal setting contract booklet in which participants write a weekly goal, which is Specific, Measurable, Action-oriented, Realistic and Time-limited (SMART) is handed out (Manaia Health PHO Ltd, 2007c). Goals are discussed the following week and participants fill-out their weekly progress (from 0-100%) towards achieving the goal (Manaia Health PHO Ltd, 2007b).

Aims and objectives of the project

The aims of the project are “for each participant to gain the necessary knowledge, motivation and skills to successfully implement long-term lifestyle changes to achieve and maintain good diabetes management and thus enhance their quality of life” (Manaia Health PHO Ltd. 2006a). The objectives of the course are listed in Figure 5.

1. Improve diabetes risk management
2. Increased adherence to recommended dietary practices
3. Increased adherence to recommended physical activity guidelines and stress management
4. Increased adherence to recommendations with medications, foot care and blood glucose monitoring according to prescription
5. Increase in participant’s perception of health, well-being and support

Figure 5. Objectives of the diabetes self-management programme (Manaia Health PHO Ltd, 2006a).

An underlying objective is to increase participant's self-efficacy in regard to their diabetes self-management. The course leaders have developed performance indicators for objectives 1-5 and these are shown in Figure 6.

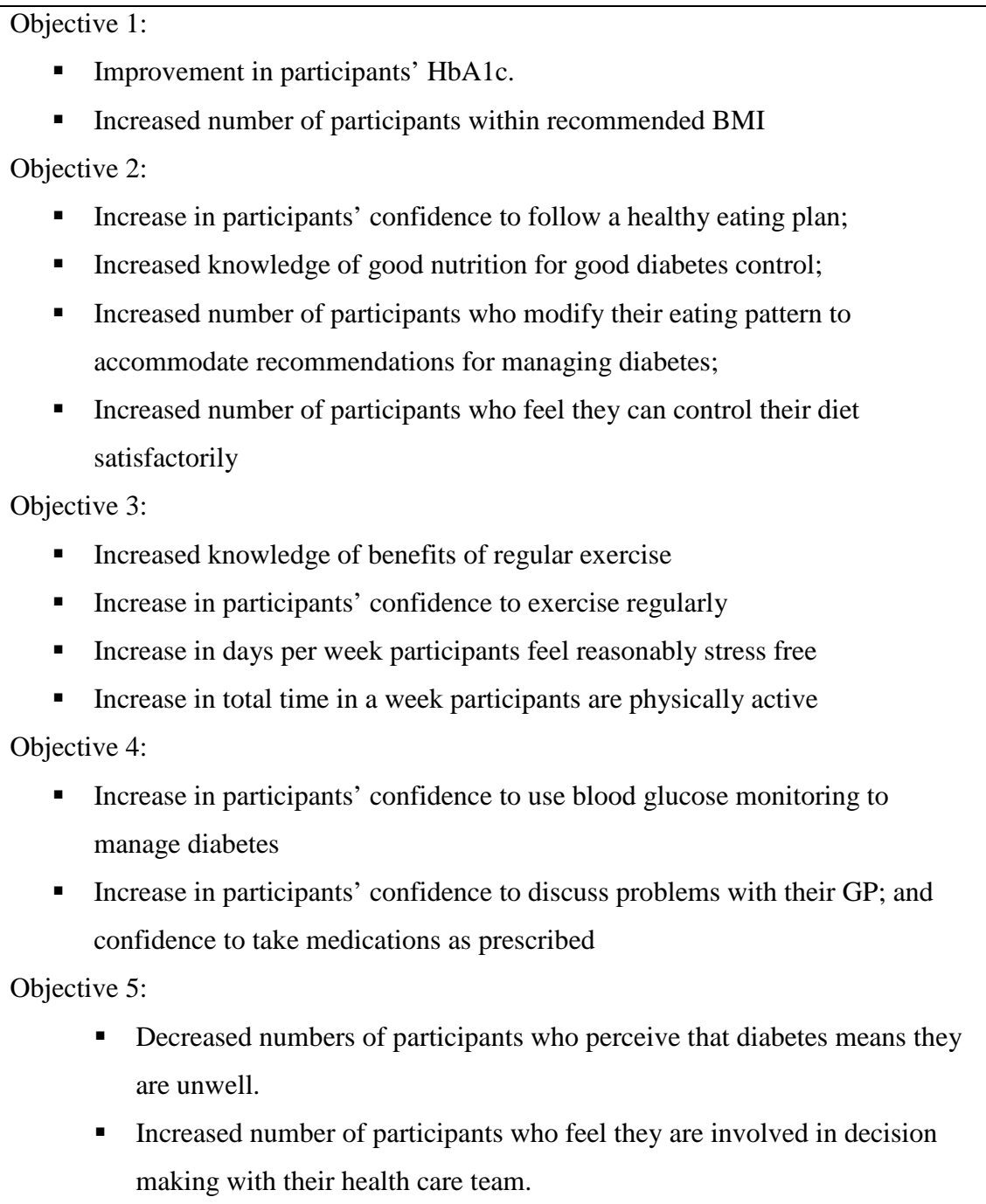


Figure 6. Performance indicators of the diabetes self-management programme (Manaia Health PHO Ltd, 2006a).

The two main psychological factors, defined as outcome measures of the self-management programme, are self-efficacy (confidence to initiate diabetes-related health behaviours) and quality of life (Manaia Health PHO Ltd, 2006a). These two factors and

their inclusion and relevance in diabetes care and education will be introduced in the following chapter.

Summary

Diabetes is a progressive disease that cannot be cured but managed. The number of people diagnosed with diabetes is increasing in New Zealand. Diabetes is one of the major health concerns in Northland, where a third of people with diabetes have poorly controlled blood glucose levels. Self-management is seen as an important aspect of diabetes care and education programmes have been developed over the last few decades, offering either individual or group education. One example of a Type 2 diabetes self-management programme is the group-based Diabetes Self-Management Programme in Whangarei, Northland.

Chapter 2 Psychology and diabetes

Self-efficacy and quality of life as components of diabetes self-management

The recent shift in regard to the conception of health and illness provided a reorientation from a model based on disease to a model based on health, which is not just the absence of disease or illness (Bandura, 1997). It led to the realisation that a major limitation in regard to the current assessment of diabetes self-management programmes is the lack of focus on psychological factors (Norris et al., 2001). Recent years have seen an increased interest in regard to self-efficacy and quality of life as components and outcome measures of diabetes self-management programmes.

2.1. Definition of self-efficacy

Bandura defines the concept of self-efficacy as “beliefs in one’s capabilities to organize and execute the courses of action required to produce given attainments” (p.3) and these may be seen as the link between knowledge and actual behaviour. Self-efficacy has also been defined as “an individual’s perception of his/her own ability to perform a specific task in a given situation” (Krichbaum et al., 2003, p.5). Self-efficacy is not concerned with the actual skills a person has, but rather with the self-belief regarding what a person can do, regardless of their skills.

2.1.1. Dimensions of self-efficacy

According to Bandura (1997) expectations in regard to self-efficacy vary along the three dimensions of magnitude, strength and generality. Each of them can be linked to different aspects of performance. Magnitude refers to the hierarchical ordering of tasks, according to their level of difficulty. People low in magnitude expectations believe they can only perform the simpler tasks compared to people with expectations high in magnitude. Strength refers to the resoluteness of a person’s beliefs that they can perform the specific task. Strength has been related to persistence irrelevant of barriers (like pain) to performance. Finally, generality refers to how self-efficacy expectations either remain in a specific situation or are generalised to other situations or behaviours (Lau-Walker, 2006; Maddux, 1995).

2.1.2. Primary sources

Self-efficacy beliefs result from the interaction of a number of primary sources of information. Bandura (1997) classifies them into a) mastery enactment experiences, b) vicarious experiences, c) verbal persuasion, and d) physiological and affective/emotional states. Maddux (1995) adds 'imaginary experiences' as a further source.

Mastery enactment experiences are the most powerful and influential source of information. Obvious failures and successes fall into this category. These experiences are viewed as providing the most authentic evidence as they are based on personal experience. Vicarious experiences refer to observational learning, modelling and imitating others that perform the behaviour. The information gained by observing what others are able to do and what consequences the behaviour evokes enables a person to form expectations about their own behaviour and its consequences. Verbal persuasion (or social persuasion) sees significant others expressing the belief that the person is capable of achieving the task in question. Verbal persuasion can help bringing about changes if the appraisal by others is realistic. The trustworthiness, expertise and attractiveness of the significant other (the source) play a role in regard to effectiveness of the persuasion. Physiological and affective states of the individual person are relied upon to provide information in regard to their capabilities of performing a task. Imaginary experiences relates to a person's capabilities of visualising possible situations and tasks, their own behavioural and emotional reactions, as well as the possible consequences to them. These imagined situations can be derived from actual or vicarious experiences or verbal persuasion (Bandura, 1997; Lau-Walker, 2006; Maddux, 1995).

2.2. Self-efficacy and diabetes

Bandura (1997) points out that people's non-adherence to a treatment/care regime arise from disbelief in their self-efficacy rather than from disease activity or physical disability. The notion of self-efficacy is viewed as particularly useful in regard to a diabetes self-care regimen because Type 2 diabetes is normally not managed with medication alone, but also with a change in lifestyle behaviours. Because the focus is on self-management over the remaining lifetime of the person and not on cure, making successful changes in behaviour is an even more important aspect of diabetes care. If a

person follows the different aspects of the care regime is difficult to assess. Even if a person with diabetes follows one part of the self-management regime this does not necessarily translate to following all aspects of the regime (Maddux, Brawley & Boykin, 1995).

2.2.1. Self-efficacy as an aspect of self-management programmes

Improving self-efficacy appears to offer a basis for education programmes, with its aim of changing behaviour in order for people to live with and manage their diabetes effectively (Bandura, 1997; Krichbaum et al., 2003; Thomas & Browning, 2005; van de Laar & Bijl, 2002). de Ridder (2004) highlights the importance of self-efficacy in dealing with any chronic illness, because it is assumed that perceptions play a crucial role in whether people with diabetes will initiate the relevant health-related behaviours or not. Self-efficacy is also believed to determine how much effort and persistence people will continue to exert with these behaviours, particularly when obstacles arise. The perceptions are viewed as being task-specific and diabetes-related self-management behaviours fit very easily into this perception. van der Bijl, van Poelgeest-Eeltink and Shortridge-Baggett (1999) divide these behaviours into three groups: a) activities (diet, medication, exercise); b) self-observation (glucose control, weight, feet check) and c) self-regulating activities (variation in nutrition, illness, stress), which are all important in order to prevent long-term complications.

Browning and Thomas (2005) distinguish between three different areas of self-management in which self-efficacy can play an important role when it comes to achieving them. These areas are: a) learning of self-control skills, b) enhancing beliefs that increase the likelihood of changing health behaviours and c) environmental factors (like family). They conclude that successful education programmes should include strategies that enhance participants' beliefs that they can master the tasks at hand.

2.2.2. Incorporation of the primary sources of self-efficacy into diabetes education

Incorporating the primary sources of self-efficacy into an education programme can be useful to moderate health behaviours (Bandura, 1997). Mastery experiences can be enhanced through practicing tasks, splitting tasks/behaviours into specific tasks and goal setting. Participants can set contracts with themselves in order to achieve these goals. Gonzalez (1990, as cited in van de Laar & van der Bijl, 2002) stresses the importance of

discussing set goals and setting new goals during each education session, and the provision of feedback by course leaders (and other participants). Participants reported satisfaction with goal setting in regard to all aspects of diabetes self-management behaviours, especially diet and exercise (Schnoll & Zimmerman, 2001; Sprague, Shultz & Branen, 2006; Weber, Baranowski & Smith, 2001). Goal setting has also been positively associated with weight loss and changes to diet in people with diabetes (Schreurs, et al., 2003).

Providing role models, brochures, demonstrating specific skills and videos can enhance vicarious learning. Group education programmes are often viewed as particularly beneficial in this regard, seeing they allow for the sharing of experiences among participants. Verbal persuasion is commonly used in education programmes and can take different forms, from providing knowledge, explanations and instructions, to convincing people to start making changes and providing encouragement and feedback once changes are being made. Finally, self-efficacy can also be improved by helping people improve their physical and psychological situation and reduce stress. People with diabetes need to learn about the relationship between “disturbances of blood glucose by stress, food and physical exercise” (van de Laar & van der Bijl, 2005, p.70).

2.2.3. Self-efficacy and chronic illness research

A number of studies have investigated self-efficacy and its impact on chronic illnesses in regard to health behaviours and functional ability. Self-efficacy appears to be an important predictor for promoting effective self-management in a range of chronic conditions. These include epilepsy (Kobau & DiIorio, 2003); sickle cell disease (Thomas, Dixon & Milligan, 1999); pulmonary disease (Scherer & Schmieder, 1996); cardiac disease (Cheng & Boey, 2002); asthma (Berg, Dunbar-Jacob & Sereika, 1997), chronic pain (Arnstein, 2000; Ashgari & Nichols, 2001); stroke recovery (Medin, Barajas & Ekberg, 2006) and arthritis (Barlow, Sturt & Hearnshaw, 2002; Prior & Bond, 2004).

2.2.4. Self-efficacy and diabetes research

An increasing number of studies are investigating self-efficacy in people with diabetes and its impact on diabetes-related health behaviours and self-management. Self-

efficacy appears to influence the uptake and outcomes of health behaviours in people with diabetes (Aljasem, Peurot, Wissow & Rubin, 2001; Hurley & Shea, 1992)

Bernal, Woolley, Schensul and Dickinson (2000) report that self-efficacy impacted positively on diet and regular medication taking in Hispanic populations. Self-efficacy is also associated with treatment satisfaction and better glycaemic control (Howarka et al., 2000). Higher levels of self-efficacy are also associated with higher levels of adherence (Sacco et al 2005; Senecal, Nouwen & White, 2000). Williams and Bond (2002) found in their Australian sample that self-efficacy was significantly associated with all three main diabetes self-care behaviours (diet, exercise and blood glucose testing). A recent study indicates that self-efficacy appears to be positively correlated to good foot care (Sarkar, Fisher & Schillinger, 2006).

2.3. Quality of life in health care

The concept of looking at people's quality of life is often used to evaluate health care services in regard to their quality and outcome for patients. Two explanations have been brought forward to account for the increased interest in quality of life in health care and health research.

Due to an increase in life expectancy, more people are diagnosed with a chronic illness during their life. Polonsky (2003) states that due to this health related quality of life, how well people are doing should be considered as one –if not the most important– clinical and research outcome. It is assumed that a good health care programme or medical intervention should improve people's quality of life. By focusing on this outcome, it is assumed that the intervention or programme will become more patient-centred. A second argument brought forward is that the larger number of treatment options available allows for a comparative assessment of these different options. By looking at improvements in quality of life, treatment options can be assessed in regard to their impact on participants' wellbeing and treatment satisfaction (Moons, Budts & De Geest, 2006; Snoek, 2000).

2.3.1. Quality of life in diabetes education and research

Over the last few decades quality of life has also increasingly become a focus in diabetes education and research. While in 1980 only one study (in Medline) focused on

diabetes-related quality of life, in 2000 167 studies emphasised this concept (Maldonato, 2005). Snoek (2000) points out that in the last decade the interest in regard to quality of life in diabetes has steadily increased. Indeed, it is now widely recognized that quality of life is as important in regard to health outcomes as the more traditional medical outcomes (Pitts & Phillips, 1998).

The European St. Vincent Declaration (1999) included in its general goals for people with diabetes to use knowledge from diabetes research to “greatly improve life and health for people with diabetes” (p.2). This would include improvement in health care experiences and enabling people with diabetes to live a life that is approaching a normal life, both in quantity and quality. The newly adopted Northland Diabetes Strategy Implementation Plan (2006) reflects the goals of the St. Vincent Declaration by aiming: “To create an environment that stops people getting diabetes, slows the progression, reduces the impact and improves the quality of life for those diagnosed with diabetes” (p.1).

2.3.2. Definition of Quality of life

Bowling (2005) defines quality of life as a grade of goodness of life, and when it comes to health outcomes as the “goodness of those aspects of life affected by health (p.7). However, defining and measuring quality of life is difficult and it has remained controversial. In general, it appears that the concept is being viewed as: a) multidimensional; b) encompassing aspects of psychological, social, and physical well-being, and c) “should reflect the patient's subjective evaluation of wellbeing rather than the health care professional's view” (Snoek, 2000, p.25).

2.3.3. Assessing quality of life

Snoek (2000) states that quality of life and its health outcomes should be assessed through people's self-reports and should include all aspects of a particular disease and its treatment regime. Johnston et al. (2004) point out when it comes to measurement of quality of life there are two divergent thoughts at this stage. Measures can either evaluate quality of life objectively or by focusing on people's expectations and values. When it comes to diabetes, quality of life can be separated into the following components: a) perceived health status, b) health-related quality of life (physical, social

and psychological), c) reduced symptoms, and d) satisfaction with the treatment (or programme) and outcome (Bowling, 2002).

These aspects enable a better understanding of the impact diabetes has on an individual's life (-style), and form a basis from which programmes/interventions can be evaluated. As a result, an increasing number of quality of life measures have been developed over the years, ranging from general to diabetes-specific measures.

2.4. Quality of life and diabetes care

Rubin (2000) points out that quality of life is an important factor in diabetes and diabetes care, as a diagnosis of diabetes can be overwhelming and can lead to a decreased emphasis on self-care. The focus on quality of life as a health outcome has led to the change in focus of programmes, emphasising the importance of the link between quality of life and commitment to diabetes self-management and care. However, as Rodin (1990, cited in Pitts & Phillips, 1998) suggests, there might still be a marked difference in regard to perception of the importance of quality of life between health professionals and people with diabetes. Health professionals may view the reduction of quality of life "as an acceptable sacrifice in return for a reduced risk in long-term complications" (p.232), while people with diabetes might not agree with this opinion.

Seeing health is often included as an important part of quality of life, the notion of health-related quality of life has been developed to assess people's experiences relating to health/illness and effectiveness of treatment. Polonsky (2000) summarises the different ways that diabetes can affect health-related quality of life. Physical wellbeing can be affected by the development of long-term and/or short-term complications, as well as an increase in physical symptoms and changes in lifestyle (due to diabetes). Psychological wellbeing, particularly mood, may be affected due to the daily demands of diabetes care. Fatigue, helplessness and struggling to adjust to diagnosis can also be associated with diabetes. Diabetes can also impact on social wellbeing, especially quantity and quality of relationships, and feeling unsupported or pushed by family/friends in regard to self-care.

Two systematic reviews have highlighted that people with diabetes report lower quality of life compared to people without diabetes, particularly in the domains of physical functioning and wellbeing. The development of macrovascular (especially coronary heart disease) and microvascular disease, associated with diabetes, also appear to lower quality of life. Treatment intensification (from diet to oral medication to insulin) initially decreases quality of life, while long-term glycaemic control increases quality of life. People with diabetes are also more likely to suffer from anxiety and depression compared to the general population. Demographic variables associated with a better quality of life are higher education and income. Men generally report better quality of life compared to women, while increase in age and being foreign-born are weaker predictors in regard to decreased quality of life (Rubin & Peurot, 1999; Wändell, 2005).

The impact of self-efficacy and quality of life in regard to diabetes education, care and uptake of behaviours on individuals has been widely studied. The increase of group education programmes as another form of education has led to their quantitative and/or qualitative evaluation. The following chapter will discuss the evaluation of overseas self-management programmes and their outcomes.

Summary

Recent years have seen an interest in psychological factors as components of health care and self-management. A particular focus is placed on self-efficacy as an outcome measure. Research has indicated that the integration of the primary sources of self-efficacy appear to be useful in regard to diabetes education. It appears that self-efficacy plays an important factor in predicting the uptake and maintenance of health care behaviours. The concept of quality of life has also been included as an outcome measure in chronic disease education and care. Research highlights the impact of living with a chronic illness on quality of life.

Chapter 3 Evaluation

Outcome and process evaluations of overseas self-management programmes and the current study

Group education programmes have been developed to educate people with chronic diseases. It is assumed that this education increases self-efficacy, quality of life and uptake and maintenance of self-management behaviours in people with chronic illnesses, while at the same time being cost-effective and relieving the burden on the health system. Self-management interventions appear to have a more beneficial impact on outcomes, both in the short- and long-term compared to other types of interventions (Steed, Cooke & Newman, 2003). Evaluations of these programmes allow for a better understanding of their impact on the self-management behaviour and lives of participants. Outcome evaluations highlight if short-term and long-term outcomes are being met, while process evaluations show what the programme achieves and if it is suitable for the population for which it is designed for. Evaluations of self-management programmes can focus on outcomes or processes or a combination of both.

3.1. Outcomes versus processes in evaluations

Outcome evaluation “examines if the program accomplishes what it set out to accomplish” (Lorig, 1991, p.17). According to the World Health Organization (WHO, 2000a) the aim of outcome evaluations should be to establish if the programme and treatments are effective. An emphasis should be placed on if, and how participants and their circumstances change after taking part in a programme or treatment and also if these changes can be related to their participation in the programme or treatment.

When it comes to the evaluation of self-management programmes objectives can focus on changes in health behaviour, health status and self-efficacy (Lorig, 1991). Rubin and Peyrot (1999) point out that quality of life is another important health outcome, which plays a critical role in the uptake of self-management behaviours and as a strong predictor of medical outcomes. Steed, Cooke and Newman (2003) discuss that evaluating self-management programmes in regard to psychological outcomes, and not just physical outcomes is important to ensure that specific programmes do indeed increase and not decrease participants’ wellbeing or quality of life. Bowling (2002)

summarises that outcome evaluations of self-management programmes need to explore whether programmes “lead to an outcome of a life worth living in social, psychological and physical terms” (p.13).

Lorig (1991) defines process evaluation as finding out what is happening within the programme. Objectives for this type of evaluation would be strictly focusing on management and teaching processes. The World Health Organization (2000) states that process evaluations help in providing a better understanding of the actual programme, what the programme achieves, and who participates in and benefits from the programme. The WHO recommends that process evaluations incorporate questions surrounding the areas of coverage and process. Questions in regard to coverage can include demographic characteristics of participants, number of participants enrolled and dropouts, and if the programme serves the intended participants. Questions in regard to processes would include the route through which participants enrolled in the programme, if the programme impacted (positively or negatively) on participants, satisfaction of participants with the programme, and if it serves the intended participants (WHO, 2000).

The WHO (2000) discusses three reasons why a process evaluation of a programme should be undertaken. First, for accountability reasons, if the programme is actually accomplishing what it is designed for. Second, a process evaluation is useful for the future development and improvement of the programme. A process evaluation can highlight strengths and weaknesses of the programme and indicate which areas need to be improved. As a final reason, the programme may be expanded into other areas or can be used as a basis to develop similar programmes.

3.2. Evaluating self-management programmes

Over the last few years a number of different international chronic disease self-management courses have been evaluated. Some evaluations focused completely on outcomes, while other evaluations incorporated process components. The main differences emerge when it comes to the evaluation of outcomes, with some placing a greater focus on physical outcomes, while others include psychological and social factors in the evaluation.

When looking at the design and content of programmes, it appears that most diabetes and chronic disease self-management courses share some similarities. Most consist of 6-7 weekly sessions, lasting from 2-2 ½ hours and have a total of 8-16 participants. Some are lay-tutor led, some by experts, ranging from a single leader (often a diabetes nurse, physician or dietician) to a team of leaders (including nurse, dietician, physician, psychologist, social worker). The programmes share similar content in regard to the topics covered. Generic topics include physical activity, medication use, nutrition, effective health service and community service utilisation, communication and relationship with health professionals and family members and stress reduction techniques. Diabetes-specific topics include recognizing and treating symptoms and measuring blood glucose levels.

3.3. Evaluating self-efficacy as an outcome of self-management programmes

Self-efficacy, the confidence to initiate and maintain self-management behaviours, is a main outcome for a number of self-management programmes. Self-efficacy can help people with a chronic illness to master the necessary skills and deal more effectively with their disease on a daily basis.

The Chronic Disease Self-Management Program (CDSMP) developed by Kate Lorig, with its focus on different types of chronic illnesses, is based on Bandura's self-efficacy theory. There have been several outcome evaluations of this course, with a focus on participants' self-efficacy.

In an UK sample, pre-test/post-test results (four months) found that participants of the course reported small improvements in self-efficacy and health distress (Wright, Barlow, Turner & Bancroft, 2003). At a 12-month follow-up the significant improvements in the previously reported outcomes were sustained, but no significant changes were found over time among the variables studied (Wright, Barlow, Turner & Bancroft, 2005). A Canadian study found significant differences in regard to improved self-efficacy and belief about general health. Participants also reported to be less distressed/bothered about their illness/health condition and less limited in their daily activities at the six-month follow-up compared to prior to the course (McGowan, 2001).

A Chinese version of the CDSMP course reported improvements in self-efficacy and health status, as well as lower hospitalisation rates at a 6-month follow-up compared to a control group (Dongbo et al., 2003). Finally, a Dutch study reported no differences in regard to self-efficacy and health status between their intervention and control group (Elzen, Slaets, Snijders & Steverink, 2007).

An evaluation of the CDSMP in an UK study at four months focused on confidence to maintain current behaviours. Participants reported the usefulness of learning and being reminded of self-management techniques (particularly goal setting and skills mastery) as a means to confidently choose self-management behaviours that suited their needs (Barlow, Bancroft & Turner, 2005). Participants from both the UK study and a Chinese study reported that they felt more confident in regard to being in control of their condition and in managing it after attending the programme (Barlow et al., 2005; Dongbo et al., 2006).

An interview-based evaluation of a self-management programme for people with chronic obstructive pulmonary disease (COPD) reported increases in coping behaviours, disease-specific self-confidence and self-determination. Participants felt better equipped in regard to coping with their disease and more confident and determined in regard to managing their disease (Monninkhof et al., 2004).

The evaluation of specific Type 2 diabetes self-management programmes over the last few years provide a better insight into how people with diabetes benefit from attending such programmes. Results from two pre- and 6 month post-outcome evaluations of a Diabetes Self-Management Program in British Columbia show that at the 6-month follow-up participants with diabetes had improved communications with their doctor and also had a higher level of self-efficacy (McGowan, 2001; McGowan, 2004). A Dutch 3-month diabetes self-management programme, with a focus on improving goal-setting, reported that nine months after completing the course participants had a reduction in their body mass index; lower systolic blood pressure and improved control of blood glucose and cholesterol (Thoolen et al., 2007).

3.4. Evaluation of self-management behaviours as an outcome

Self-management behaviours, the necessary skills to care for one's chronic condition, include both physical and psychological components.

A Canadian and Chinese study found significant differences in regard to improved management of cognitive symptoms when evaluating the CDSMP (Dongbo et al., 2003; McGowan, 2001). Increased physical activity was reported by the Chinese study and a UK study at a 4-month follow-up (Barlow et al., 2005; Dongbo et al., 2003). The UK study reported no changes in regard to self-management behaviours between the 4- and 12-month follow-ups, which suggests that improvement were maintained over time. A Dutch course evaluation reported no significant differences in regard to the uptake of self-management behaviours between the intervention and control groups (Elzen et al., 2007).

The evaluation of a CDSMP in the UK focused on the current practice of self-management behaviours (at 4-months), while at 12-month follow-up questions focused on participants' ability to maintain and/or initiate self-management behaviours. The reported theme was initiating successful self-management (goal setting, feedback from group, confidence to manage, skills to manage, relaxation, exercise) at 4- and 12-months. Participants also reported specific self-management behaviours that they used and initiation of new behaviours during the course (Barlow, Bancroft & Turner, 2005). Participants attending a COPD-self-management programme reported an increase in exercise and endurance capacity, relaxation and breathing techniques after attending the programme (Monninkhof et al., 2004).

One study of a diabetes-specific group programme in Canada reported that at 6-month follow-up participants coped better with their symptoms compared to pre-test results (McGowan, 2001). Another Canadian study reported that at 6-month follow-up participants had made changes to their diet, were more likely to take their medications and reported improvements in their communication with a physician (McGowan, 2004).

The UK Diabetes X-Pert Programme, a programme aiming at developing skills and increasing confidence in its participants, was used to assess outcomes at baseline, 4- and 14-month follow-ups. Results show that at 4 months there was a significant difference

between intervention and control group. Participants attending the course showed better improvements in regard to a number of biomedical outcomes (HbA1c, body weight, BMI), a reduction in diabetes medication and increased self-management behaviours. Differences at 14 months were still significant in regard to some biological outcomes and self-management behaviours (Deakin, Cade, Williams & Greenwood, 2006).

A study of the UCL-Diabetes self-management programme in the UK showed that at three-months the intervention group had significantly increased and maintained exercising, blood glucose monitoring and following dietary guidelines compared to a control group (Steed et al., 2005).

3.5. Evaluating quality of life as an outcome of self-management programmes

The impact of attending a chronic or disease-specific self-management course on participants' quality of life has also been evaluated as an outcome over the last few years.

An Australian Outcome Survey was used to evaluate 142 group chronic disease self-management courses (pre-and post course measure). Improvements were reported in regard to skill and technique acquisition, self-monitoring and insight. Smaller improvements were reported in regard to engagement in life, health-directed behaviour, attitudes, and navigation of health services and social support (Nolte, Elsworth, Sinclair and Osborne, 2007).

A cognitive-behavioural diabetes self-management programme developed for Spanish speakers in the US found that, compared to pre-assessment, participants showed greater knowledge, improved wellbeing, lower levels of diabetes-related emotional distress and a reduction in lipids and HbA1c at 3- and 6-month follow-ups (Mauldon, D'Eramo Melkus and Cagganello, 2006). After attending a Canadian diabetes self-management programme, participants reported overall better health; experienced less distress in regard to their symptoms and less pain (McGowan, 2004).

The UK Diabetes X-Pert Programme, a programme aiming to develop skills and increase confidence in their participants was used to assess outcomes at baseline, 4- and 14-month follow-ups. No differences were found in regard to quality of life between

the participants of the programme and a control group (Deakin et al., 2006). Participants of the UCL-Diabetes self-management programme showed significant improvements in regard to diabetes-specific quality of life compared to a control group at a 3-month follow-up (Steed et al., 2005).

The focus of the study evaluating a COPD-course was on participants' perception in regard to the effects of the programme on their quality of life. Results indicate that participants perceived the course, especially the fitness programme, to be impacting positively on their daily life and wellbeing. Participants reported feeling safer because they participated in the programme and received guidelines (Monninkhof, et al., 2004). The participants of the CDSMP in China reported having a more positive perspective and outlook in regard to their chronic disease and on their future after attending the course. Participants also mentioned that their mood had improved and they were more equipped to deal with negative emotions (Dongbo et al., 2006).

3.6. Process evaluation

A small number of studies reported assessing aspects of processes in their overall evaluation. Most studies reported attendance rates as one way of subjectively evaluating the self-management programmes. Reported attendance rates were high, ranging from 73%-100% of participants attending all sessions (Barlow et al., 2005; Dongbo et al., 1996; Elzen et al., 2007; Mauldon et al., 2006; Deakin et al., 2006).

Subjective process evaluation of the programmes was reported ranging from obstacles which participants overcame to attend the sessions (work schedules, transportation, childcare) to personal comments by participants to healthcare workers or members of the research team (Mauldon et al., 2006; Monninkhof et al., 2004). Results from the Dutch-based CDSMP show that participants rated the course positively (8.5 out of 10) and found it useful and enjoyable. Participants were also satisfied with the preparation, teaching methods and content, group size, length of sessions and the room used. At the same time "25% of the participants found that the course was strenuous" as the sessions were seen as lasting too long (Elzen et al., 2007, p.1837).

Barlow et al. (2005) report that participants attending a UK-based CDSMP spoke of the environment as supportive and reassuring. Participants stressed the importance of the

programme in regard to sharing and comparing experiences and receiving support. Information sharing between participants and tutors was also seen as a positive aspect of attending the programme.

Participants of the Chinese CDSMP summarised their experiences of attending the course under two themes. 'Perception of the content of the CDSMP course' included discussions around the contents that participants liked, disliked and the ones that could not be learned elsewhere. 'Perception of the method of course delivery' reflected participants' views on the positive aspect of group teaching, including experience sharing, support and improving together. Finally, participants provided practical suggestions on recruitment by passing information on to others (Dongbo et al., 2006).

For participants of the COPD programme group teaching was an important source of peer support, recognition and a move away from social isolation (Monninkhof et al., 2004). Canadian participants of a CDSMP named group teaching and interaction as the most important aspects (McGowan, 2001). Participants shared which aspects of the programme had been useful, which they wouldn't have learned anywhere else and which were disliked.

3.7. Methods used for the evaluations of self-management programmes

Most of the previously discussed evaluations used quantitative methods to assess outcomes of group-management programmes. Questionnaires used in these evaluations ranged from programme-specific (in the case of the CDSMP), to disease-specific, to generic measures. Results from most of these evaluations appear promising in regard to the effectiveness of group self-management programmes with significant reported improvements in a wide range of outcome variables.

Overall, the different quantitative measures used appear to assist in evaluating the health outcomes of participants. However, as some are designed to cover a wide range of chronic illnesses, it is unclear whether participants with specific chronic diseases benefit from the course in the same way. While participants might have improved overall in self-efficacy, self-management behaviours and health status, these improvements may not have happened in areas specific to their disease. Generic measures might be, as

Elzen et al. (2007) point out, “too broad concept to measure the specific self-efficacy beliefs of patients with chronic diseases” (p.1839).

At the same time, while diabetes-specific measures allow for a better understanding in regard to the effects of the programme on diabetes-related self-efficacy, self-management and quality of life, they do not allow for transference of these effects to participants’ general health and life. Some studies mentioned that no effects were found in regard to specific aspects of the evaluation. Monninkhof et al. (2004) mention as these results were contrary to subjective information received, a qualitative study was undertaken to further assess the effects of the programme on participants.

In recent years, the benefits of qualitative evaluations have been recognized as a way of enhancing and completing quantitative data and providing a different insight into the benefits for participants. Qualitative evaluations might allow for the capture of unique issues that questionnaires fail to address. Very few self-management programmes have been evaluated using qualitative methods. As Monninkhof et al. (2004) report, the qualitative evaluation of the COPD programme helped to make sense of the discrepancies that arose when comparing the quantitative results and subjective information provided by participants and healthcare workers.

It appears that themes that emerged from the qualitative evaluations of self-management courses mirror some information gained from quantitative measures. They provide a better understanding of the benefits of attending these courses for participants. While a number of different quantitative measures might provide similar results as the themes that arose from a qualitative evaluation, an individual questionnaire would have been potentially not capable of identifying all the results. Indeed as Monninkhof et al. (2004) discuss, their study suggested a number of aspects that were not adequately captured by the quantitative measure that they had used in a previous evaluation of the course. Results from the qualitative studies also indicate that quantitative measures might fail to capture the full scope of participants’ experiences from participating in a group programme. Fu, Ding, McGowan and Fu (2006) point out that their qualitative evaluation allowed them to identify the uptake of new behaviours, an aspect not measured in the quantitative evaluation of the programme.

3.8. Evaluation of the Diabetes Self-Management Programme in Whangarei

A quantitative evaluation questionnaire with a particular focus on self-efficacy in regard to diabetes-related self-management behaviours has been developed as one way of assessing the outcomes of the programme, using it as a pre/post measure (Manaia Health PHO Ltd, 2007d). There are no results available at this stage.

A process evaluation questionnaire has also been developed. This measure asks participants to indicate (weekly) for each topic (total of 11) how much they learned, and either how useful the information was or how confident they are that they will use this information in their day-to-day life. Three items are used as a specific process measure to evaluate the overall course. These items determine the course worthiness, topic suggestions for a follow-up session, and the usefulness of the teaching tools. Participants are also encouraged to provide additional comments if they wish to do so (Manaia Health PHO Ltd, 2006b).

3.9. Current study

The current study is a qualitative evaluation of the newly organised and run diabetes self-management programme by Manaia Health PHO in Whangarei. As there are no results available from the quantitative evaluation this study will be the first to provide information in regard to the effectiveness of the programme. The present study is a combined outcome and process evaluation to explore the impact of the programme on participants' perception of their self-efficacy and quality of life and how they experience the course.

Specifically the aims of the study are:

To evaluate the impact of the diabetes self-management course:

1. How do participants perceive the course improved their self-efficacy (especially confidence) in regard to diabetes-related behaviours?
2. Has attending the course impacted on participants' perception of their quality of life?

To evaluate the process of the diabetes self-management course:

3. What are participants' experiences of the self-management course?

The use and benefits of qualitative methods in health research evaluations in general and in regard to this study will be discussed in chapter 4. The methodology underlying the study will also be introduced in the following chapter.

Summary

A number of overseas self-management programmes have been evaluated using either quantitative or qualitative evaluation methods. Results highlight the usefulness of self-management programmes in regard to improving a wide range of outcome variables for participants, including self-management behaviours, self-efficacy and quality of life. While quantitative evaluations provide general information in regard to participants' improvements, qualitative evaluations are able to capture the full experience of participants and add information that is not captured by a quantitative measure. The Diabetes Self-Management Programme in Whangarei currently uses a quantitative measure with a focus on self-efficacy but results are not yet available. The current study will be a qualitative evaluation of the course to provide a better understanding of participants' experiences.

Chapter 4 Qualitative evaluations in health research and interpretative phenomenological analysis

“Qualitative research is a field of inquiry in its own right”(Denzin & Lincoln, 2000, p.2). It locates the researcher in the ‘real’ world, allowing for the collection of different materials, including the perceptions of the participants. Qualitative research stresses the close relationship between the researcher and the researched (participant or text) and that reality is socially constructed. It is concerned with the meaning that people give to their experiences, their understandings of their lives and how people account for their actions (Gray, 2004; Pope & Mays, 2006).

There are a number of different methodologies underlying qualitative research that are used within the field of health research. A fairly recent development is interpretative phenomenological analysis, with a focus on how individuals construct, “make sense of, and talk about issues concerning health and illness” (Smith, Flowers and Osborn, 1997, p.68). At the same time, grounded theory methods are used within health research as a useful technique to aid in analysis of the data (Pidgeon & Henwood, 1997). This chapter discusses the use of qualitative methods when evaluating health programmes. It also introduces the methodology underlying interpretative phenomenological analysis and how some aspects of grounded theory methods assist in the subsequent data analysis.

4.1. Qualitative methods in evaluations of health programmes

The last two decades have seen an increase in qualitative studies within the area of health research. Hutchinson (2001) points out that qualitative methods in practice can be used to a) influence thinking, b) develop and evaluate interventions, c) evaluate programmes/clinical trials and d) solve clinical problems.

Patton (1987) highlights that some questions and situations arising out of evaluations can be better looked at using qualitative research strategies because they provide a more powerful and appropriate picture of the situation. One of these situations arises when evaluating whether the outcomes of programmes match the needs of the individual clients. In this case it is expected that the outcomes will differ among clients and the

meaning that these outcomes have to clients will also differ depending on the client. The focus of an evaluation in a case like this should therefore be on how, or if, clients' lives changed over the course of the programme and beyond, and also what meaning the clients ascribe to the resulting outcomes.

Qualitative methods in evaluations can also help to look at the quality of programmes. They allow for a subtler look at what makes a difference in regard to the outcomes for participants and an in-depth look into differences that go beyond the standardised scales of quantitative methods. Qualitative methods in evaluations have the potential to provide descriptions that explain in detail the differences in outcomes (and lives) of participants that attended the same programme and an insight into 'why' they answered a questionnaire differently. Looking at the quality of programmes also allows for a better understanding of what the attendance and content of the programme means to the participants and how they experienced the programme. While quantitative measures may not find statistically significant differences among participants in regard to pre- and post-outcome measures, detailed and in-depth descriptions of people's experiences of what the achieved outcomes mean to them in their lives may provide a different picture in regard to the quality and benefits of the programme. As Patton (1987) points out the "differences may simply be qualitative rather than quantitative" (p.30).

4.2. Qualitative evaluation and the current study

Choosing a qualitative evaluation approach appears to be most appropriate for the aims of the current study. This evaluation incorporates a process evaluation component (participants' experiences of the self-management course) and two outcome evaluation components (participants' perception in regard to self-efficacy and quality of life); a qualitative approach allows for an in-depth evaluation of all three components.

The qualitative evaluation of the course may highlight benefits, strengths and weaknesses as experienced by participants that a quantitative evaluation may not capture. Using qualitative methods allows gaining a better understanding of participants' experiences of the course and how these experiences are related to changes in self-management behaviours, self-efficacy and quality of life. Results of this evaluation can be used to suggest pragmatic changes that participants feel would enhance the course and possibly health outcomes. Finally, from a practical perspective, as the programme only runs three times a year, with a maximum of 12 participants, a qualitative evaluation requires only a small number of participants before saturation of the topic is reached.

4.3. Methodology: Interpretative phenomenological analysis

Interpretative phenomenological analysis (IPA) was specifically developed to provide a better understanding, within health psychology and mainstream psychology, of people's experiences of health and illness. It is increasingly used within the areas of health, clinical and social psychology, especially in the United Kingdom. Recent years have seen an interest in this type of analysis in other countries like the United States, Canada, Australia and New Zealand as well as in other areas of health research. IPA at its core is a phenomenological approach but it is also theoretically linked with hermeneutics and symbolic-interactionism (VE, 2008).

4.3.1. Interpretative phenomenological analysis's link to other theoretical approaches

IPA, as a phenomenological approach, focuses on people's worlds, experiences, and perceptions in regard to a state or event and not on providing objective accounts of these states or events. Patton (2002) points out, as the main focus of phenomenology is gaining a better understanding of everyday experiences, a wide range of phenomena can be studied, including emotions, organisations and programmes. Of particular interest is how people make sense of their experiences in regard to the phenomenon and how they integrate it into their worldview.

IPA adopts, through its theoretical link with hermeneutics, a focus on interpretations of how people make sense of their world (VE, 2008). Hermeneutics also allows for the interpretation of texts, how people make sense of these and place them in their cultural

and/or historical context. Hermeneutics proposes that the interpretation of a text can never be the truth, it is always only an interpretation undertaken by a specific person in a certain situation and time. This approach enables a researcher to “establish context and meaning for what people do” (Patton, 2002, p.115).

Finally, some of the aspects IPA shares with symbolic-interactionism, are its rejection of positivism and a focus of study on the meanings that people ascribe to their experiences of states and events in their world and how they interpret these. Symbolic-interactionism stresses that people create a shared meaning of states and events through their social interactions. Reality is therefore a result of this shared meaning and can be modified through a person’s interpretation, when dealing with the states or events (Patton, 2002).

4.3.2. Research examples using interpretative phenomenological analysis

Due to its focus on the meaning of people’s experiences in regard to a topic IPA is useful in the study of a wide range of subject areas in psychology and in regard to health research in particular (Smith & Osborn, 2003). This is shown in the diverse range of psychological research questions, within the area of health research, that have used IPA in recent years. Examples include

- Adaptation to diabetic renal disease (King, Carroll, Newton and Dornan, 2002)
- Re-appraising HIV testing (Flowers, Duncan and Knussen, 2003)
- Is Quality of Life a health concept? (Hendry & McVittie, 2004)
- The experience of adult visible acne (Murray & Rhodes, 2005)
- Management of children with ADHD (Bull & Whelan, 2006)
- Patient’s experience of powerlessness (Aujoulat, Luminet and Deccache, 2007)

4.4. The current study and aims of interpretative phenomenological analysis

The current study follows guidelines for interpretative phenomenological analysis to evaluate the diabetes self-management programme in Whangarei. IPA, with its origins in health psychology, is an appropriate methodology when looking at all three components of this evaluation.

Aims of the study are to develop a better understanding of participants' experiences in regard to the programme and their perceptions of its impact on their self-efficacy and their quality of life. These aims correlate very well with IPA's main aim of exploring people's view of the world "and to adopt, as far as possible, an 'insider's perspective'" (Smith et al., 1997, p.51).

The evaluation of the diabetes programme is interested in participants' accounts of experiences of the programme, as this potentially allows for a better understanding of how, and which aspects of, the course made a positive or negative difference in regard to participants' lives. It allows for a better understanding of how participants perceive the course impacted on aspects of their selves (self-efficacy) and their life (quality of life). This is reflected by IPA's aim at understanding people's lived experiences and how they make sense of their world (personal and social). IPA and the evaluation are interested in participants' subjective accounts of the topic(s) in question (Smith & Osborn, 2003).

Two evaluation components focus on participants' perceptions, and the potential changes in perception in regard to self-efficacy and quality of life, after attending the programme. Participants might start making changes to their lifestyle while attending the programme and it is important to gain an understanding of how participants make sense of these potential changes to their lifestyle, health and outlook on life. While the focus is on participants' perceptions, on what people report, these are closely linked to participants' cognitions and feelings about the impact of the programme on their self-efficacy and their quality of life. IPA recognizes the importance of cognitive entities, how the person feels and thinks about a specific topic, event or state and the meanings people ascribe to these (Smith & Osborn, 2003).

IPA assumes that there is a connection between the way people talk about a topic and their cognitive and emotional states (Smith & Osborn, 2003). This connection between a topic and cognitive and emotional states is especially important in the current study in order to examine how people make sense of the programmes' impact on their self-efficacy and their quality of life. As the focus is not only on participants' experiences, but also on participants' perceptions, using an IPA approach allows for an

examination of the underlying cognitive processes that lead to these perceptions and how participants relate these to the benefits of attending the programme.

The emphasis on a qualitative rather than a quantitative evaluation of the diabetes self-management programme allows for the hearing of participants' voices (positive or negative) in regard to the programme itself, and also in regard to what they see are the important or relevant changes to their self-efficacy and quality of life. Participants may have different opinions in regard to the benefits of the programme and more importantly in regard to the areas of their life upon which it made an impact. Depending on their personality or background, some participants may find it easier to share aspects about the changes to their self-management behaviours and their quality of life. According to IPA, people not only use different forms and different levels (more or less encouragement) of self-reflection but also view the world/topic in very different ways from each other. This difference in viewpoints depends on a person's personality, life experiences and motivations (Smith & Osborn, 2004). People may also prefer not to disclose certain aspects of their thoughts and emotions in regard to a topic or may have problems expressing these thoughts and emotions in their talk. Smith and Osborn (2003) point out that often it is not possible to get directly to the viewpoint of the person it is therefore important that the researcher interprets the cognitive and emotional states of the person from their talk.

IPA recognises that while the account/viewpoint of the person is an important start and the researcher should try and attempt "to understand the world from the perspective of one's participants" (Smith & Osborn, 2004, p.230) it is necessary to interpret the account. The researcher should aim to gain an understanding of what the person is trying to convey. The next step is to find out the meaning behind what is being talked about, i.e. what does having this condition mean to a person, how does the person feel about having this condition. This aspect of IPA fits very well with all three components of the evaluation, in interpreting the meaning that participants' ascribe to the impact the programme had on their self-efficacy and their quality of life. The current evaluation has the potential to highlight the meaning participants ascribe to attending the programme, the individual programme components and how well the objectives of the programme reflect participants' opinion of changes to their life. In regard to participants' lived experiences, this evaluation may highlight what it means to have

diabetes and its impact but also how the programme has changed their confidence and their life accordingly. The evaluation has the potential to help participants make sense of their experience of having and living with diabetes, while at the same time reflecting the changes that occurred during and after attending the programme.

Different strategies in regard to IPA have been developed in regard to research and these, together with a number of grounded theory methods that have been utilised in the analysis, will be discussed in Chapter 5. The following chapter provides the introduction to the practical component of the thesis, with a principal focus on introducing the research, participants, researcher involvement and analysis.

Summary

Qualitative evaluations are increasingly used in health research and are particularly useful in assessing the quality of self-management programmes and to capture participants' experiences and perceptions. As the current study focuses on these three aspects, with an emphasis on participants' subjective accounts of the topic, a qualitative evaluation appears to be the most appropriate choice. Interpretative phenomenological analysis, with its focus on participants' experiences of health and illness and emphasis on a connection between a topic and people's cognitive and emotional states, is a suitable methodology to guide this research.

Chapter 5 Method

The current study and utilised strategies

5.1. The current study

The current study is a qualitative evaluation of the diabetes self-management programme in Whangarei. The focus of the study is on participants' experiences of the course itself, and on how they perceive that the course impacted on their self-efficacy and quality of life in regard to managing and living with Type 2 diabetes.

5.2. Ethical considerations

The ethics process started with a research proposal to the programme leaders and the Clinical Advisory Committee of Manaia Health PHO. The study was reviewed and permission was granted, contingent on approval by an ethics committee, by the Clinical Advisory Committee in July 2007. Following this, a proposal was sent to the Health and Disability Ethics Committees, Northern X Regional Ethics Committee in Auckland in August 2007 and the study was approved on the 17th September 2007.

5.3. Accessing potential participants

All of the potential participants of the study had been diagnosed with Type 2 diabetes and attended one of two diabetes self-management courses offered by Manaia Health PHO between July and December 2007. Initial introductory contact with the potential participants was made during the self-management courses themselves. At the beginning of the first session, I provided a brief overview of the study and attended all sessions to give participants the opportunity to ask questions in regard to the study and to develop a relationship with me.

Upon completion of the course one of the course leaders at Manaia Health PHO sent out the information sheet (attached as Appendix A), describing the study in more detail, to the participants. This invitation to participate also included a contact form (attached as Appendix B) to be returned to Manaia Health PHO. Through this process privacy of potential participants was ensured, seeing I had only access to the returned forms of people willing to participate in the study but not the contact details of all people who attended the two courses.

Fourteen people with Type 2 diabetes attended the two courses during July and December 2007. Of these, 3 only attended the initial session and had to drop out due to work commitments and transport issues. They are currently on the waiting list for the 2008 courses. One person attended two sessions and did not return for subsequent sessions. This left ten people that attended 4-6 sessions. Nevertheless, all fourteen people with Type 2 diabetes were invited to participate in the current study. The programme offers participants the opportunity to bring along a support person and/or caregiver. These support people were not included in the current study.

5.4. Participants of the study

Overall, 7 people returned their contact forms to participate in the current study and were subsequently contacted for the interviews. Demographic data was collected from the participants at the initial interview and analysed. The analysis revealed that participants comprised 4 females (57%) and 3 males (43%). Their ages ranged from 42 years to 77 years. Three participants were in the age range of 70 years and older, 3 participants were in the 50-59 years of age group and 1 participant was in the 40-49 years of age group. This age range reflects the national averages of onset and diagnosis of diabetes in New Zealand

Five of the participants, when asked about which ethnic group they belonged to identified themselves as New Zealand European or New Zealander, while the two remaining participants identified themselves as New Zealand Māori and Indian respectively. Four participants were married or had a domestic partner (57%), two (28.5%) were widowed and one was single.

5.4.1. Participants' involvement in the study

During the 6-week course participants had the opportunity to meet me and ask questions regarding the study. After the course the information sheet and contact form were sent out to participants and those interested in participating in the study were asked to return the contact form, if possible within four weeks following the end of the course. As soon as I received the contact form, participants were contacted via phone or email and an appointment for the initial interview was made.

Participants had the choice of where the interview took place, either at their home or at an office at Manaia Health PHO (where the course had also taken place). Four participants preferred to be interviewed at the office while three participants chose to be interviewed at their home. During the interview, suitable food and beverages were provided to the participants. Each initial interview lasted between 1 ½ and 2 hours and all were tape-recorded. Prior to the initial interview participants were verbally reminded of their rights (an information sheet was also available if participants expressed the wish to read it again) and that the tape-recorder could be turned off at any time if they expressed this wish. Participants were also asked to fill-out a demographic questionnaire (attached as Appendix C).

Three months after the initial interview participants were contacted again and a short follow-up interview was conducted via telephone. Participants had the choice of date and time when this interview was to take place as well. Each of the follow-up interviews lasted between 15 and 20 minutes and notes were taken during the conversations.

IPA's strategies in regard to interviewing guided aspects of the current study. To achieve a positive outcome the interviewer needs to ensure that the interview takes place in a setting and during a time that is comfortable and convenient for the participants and that participants are at ease during the interview. IPA encourages the use of recorders during the interview process, because this allows for a fuller more detailed record of the interview, is less disturbing to the flow of the interview, and allows for better establishment of rapport compared to note-taking (Smith & Osborn, 2003).

The initial interview focused on the participants' experiences of the course and their perceptions in regard to their self-efficacy and quality of life. The follow-up interview was used to discuss topics and themes that had emerged from the data of the initial interviews and to confirm if participants agreed with these. As Smith, Flowers and Osborn (1997) point out, relating feedback allows for a stronger involvement of the participants.

The follow-up interview also provided an opportunity to inform participants in regard to the research process itself and to see if participants' opinions in regard to aspects of the course had changed, and if they had changed any of their diabetes-related behaviours (as discussed in the initial interview) or initiated new behaviours.

Participant confidentiality was discussed at the initial interview and participants were again reminded of this at the follow-up interview. They were advised that no identifying information would be included in the transcripts and that only I would know each participant's identity. Participants were allocated a number from 1-7, which did not reflect the order in which interviews took place (as an added way to ensure the confidentiality of participants that had decided to have their interviews at the office), as the only way of identifying and 'personalising' each participant.

5.5. Analytic strategies

Interpretative Phenomenological Analysis (IPA) was chosen as the analytic approach to the interview data as it allows for a better understanding of individual' experiences in regard to the topic in question. IPA is concerned with cognitions and emotions. Insight is gained in regard to individuals' perceptions and areas where perceptions are reasonably consistent across participants. As an analytic approach it can highlight connections between participants' verbal information and their cognitive and physical state. At the same time it acknowledges the researcher's own perspective and role in the interpretation during data analysis. This approach guided the data gathering in several ways.

The sample size was small but IPA studies generally have small sample sizes, allowing for a time-consuming analysis of individual transcripts. The aim is to provide detailed information in regard to each participant's perceptions and experiences and not to generalise the findings. Smith and Osborn (2003) point out that for a novice researcher, a reasonable sample size would consist of five or six participants. The actual number of participants would depend on the richness of the cases, impacting constraints and, to a large degree, on how many people interested in the topic are prepared to be involved in the research.

Semi-structured interviews were seen as the most suitable choice for this study. With IPA's focus of analysis on the perception and sense making of participants in regard to a specific topic/experience, it recommends the use of semi-structured interviews as the most flexible way to collect the data. While the researcher has a set of questions, these are used as guidelines, and semi-structured interviews do not require these to be in a specific order, asked in exactly the same way, or even to be included at all. This allows the interviewer to follow the flow of the responses of the participants and to follow-up interesting and previously unpredicted areas and concerns that may arise during the interviews (Smith & Osborn, 2003).

Over the 6 weeks duration of the course the participants and I had an opportunity to get to know each other and using semi-structured interviews allowed for a dialogue between us. IPA stresses the importance of the relationship between the researcher and the researched. Research is viewed as a dynamic process, in which the researcher takes on an active role and a more democratic relationship develops between the researcher and the researched (Smith et al., 1997).

Smith, Flowers and Osborn (1997) point out that while a conversation takes place during the interview, it is reasonably one-sided, with the researcher being involved as little as possible to allow the story to be told by the participant. In the case of the current study, being an observer of the course myself ensured a more in-depth knowledge of topics that were discussed during the course and issues that had arisen. This allowed for more of a dialogue between the participants and myself in regard to the experiences of the course, which helped participants to settle before the interview progressed to questions in regard to self-efficacy and quality of life.

For the initial interview I had developed a number of questions focusing on the three aspects of the evaluation (experiences of the course, perceptions of self-efficacy and quality of life) and these are attached as Appendix D. While most questions were raised at some stage during the interview and not necessarily in the expected order, some questions were not asked explicitly if participants brought these topics up themselves. Using semi-structured interviews allowed for a move away from the topics in questions when participants brought up topics and issues that I had not anticipated. This enabled further conversation and exploration of some unexpected topics, which provided a

richer insight into participants' perceptions in regard to their specific diabetes-related behaviours and quality of life.

Smith, Osborn and Flowers (1997) raise the point that talking about health conditions with participants can be stressful (for both sides), and while the participants disclose private information about themselves the same is not done by the researcher. However, disclosing private information partly depends on the relationship between researcher and the participants. As the participants and I had developed a relationship during the 6-week programme I had already disclosed some private information in this context. This included a personal interest in regard to living with diabetes and the quality of self-management programmes as a first degree relative of mine was living with diabetes at this stage and had recently attended a self-management programme elsewhere.

The follow-up interview was a short phone interview, which allowed me to provide participants with a broad overview of the research progress and to provide feedback in regard to agreements and disagreements in regard to the course by all participants. The interview also enabled participants to describe anything that had changed for them, either in regard to their experiences of the course or their diabetes-related behaviours. Participants were asked two more questions at the follow-up interview. These questions were about maintaining diabetes-related self-management behaviours (as discussed at the first interview) and possible initiation of new behaviours since then. Participants were asked to elaborate in regard to these two questions. Questions that were used during this interview are attached in Appendix E.

Reporting preliminary analysis results back to the participants, clarifying if these make sense to them, and also if there have been changes in their perception in regard to the discussed interview, are a number of strategies employed in IPA analysis to ensure a stronger involvement of the participant in the research process. The participants' responses to the preliminary results and any changes that occurred over time can become part of the written-up analysis (Smith et al., 1997). An evaluation of studies, following IPA, reported that most conducted face-to-face interviews, while some used telephone or email interviews (Brocki & Wearden, 2006).

5.6. Data analysis

The initial interviews were audio taped and transcribed verbatim. Transcriptions included pauses, researcher and participant words and acknowledgement of emotion (e.g. laughter). Summaries of information provided by third parties (e.g. spouses) and descriptions by the researcher in regard to shown materials (e.g. brochures, blood test results, medication) were added to the transcriptions. The first interview was transcribed into stand-alone copies. All transcription was undertaken by the researcher, which allowed for a deeper immersion in the data. During the follow-up interview notes of key points were taken by hand and added to the previous stand-alone copies.

5.6.1. IPA data analysis strategies

Using IPA strategies, the researcher is trying to make sense of the person's account during analysis (Smith, Jarman & Osborn, 1999). The resulting account is a joint account of researcher and researched, with the researcher taking a central role in both the research and the analysis (Smith et al., 1997; Smith & Osborn, 2003).

Interpretations of the account are therefore dependant not only on the participant's ability to communicate their cognitions and emotions in regard to a topic, but also on the researcher's ability to reflect and analyse these accordingly (Brocki & Wearden, 2006).

A number of suggestions are offered on how to analyse data using IPA methods but it is possible to adapt the method of analysis to the specific research. The current study made use of this flexibility by following IPA methods during the data analysis (Smith, et al., 1999) along with three grounded theory methods, which provided additional tools to aid in data analysis (Charmaz, 2000).

1) Looking for themes in the first case (IPA)

This included reading and re-reading the transcripts and notes from the follow-up interview and making notes of interesting and/or significant responses from the participants. The main aim was to become familiar with the content of the transcript, noting new insights, summaries, connections, similarities and differences in each individual account. As this evaluation focuses on three different components (course experience, self-efficacy and quality of life), I did not expect to find an overarching theme for all the data but rather three different themes reflecting each component.

Transcripts were read keeping these individual components in mind and themes were placed into the component where they seemed most fitting.

2) Connecting the themes

This stage involved the ordering of themes, finding connections between themes that emerged during the first stage of analysis. Themes were starting to be clustered together to create an overarching theme, while still remaining within the boundaries of the different evaluation components. During this process the data gained from the follow-up interviews was also used to connect it with themes from the initial interviews. A fourth and unanticipated component was created once the notes from the follow-up interview were analysed more closely as themes emerged that could not be connected to the three evaluation components.

Some themes may be dropped at this stage of analysis, seeing these might not fit well or only limited evidence is available to support these themes. As there were only a small number of participants, I decided to include some themes that were raised by a minority of participants or even just one participant. These themes appeared to be of particular importance to these individual participants and even with limited evidence or support they added new information that provided a bigger picture and was not captured by other themes.

This stage was also used to make decisions where certain themes would be placed, as they may have fitted into more than one of the three components. For example, the subtheme “confirmation of having diabetes” could have been placed in each of the three components. After re-reading the accounts the decision was made to place this theme into the component regarding self-efficacy as comments focused on the cognitive aspects in regard to accepting the diagnosis.

3) Continuing the analysis with other cases

At this final stage the individual analyses of the transcripts are combined. This was done by repeating the initial analysis for each interview, while looking for similarities and differences in the accounts of different participants. While combining the individual transcripts I noticed that information provided by participants sometimes added to information provided by previous participants. It appeared as if participants

were having ‘conversations’ with each other or finishing each other’s sentences when discussing some themes. As a way of capturing these ‘conversations’ and to include participant’s voices the results will be written as a narrative. The flow in regard to these ‘conversations’ is further enhanced by the decision to only identify participants with numbers, leaving only a ‘small gap’ when combining their individual voices into a ‘conversation’.

Following the analysis of all interviews, final themes are developed. Decisions about the inclusion of themes are now based on prevalence, richness within the data and if a theme helps to account for other themes (Smith et al., 1999; Smith & Osborn, 2003). Most final themes, and especially subthemes, were included based on their prevalence (the majority of participants discussed them) and the richness of the existing data. However, the analysis highlighted differences among participants when evaluating the self-efficacy component, leading to the creation of the subtheme ‘individual participants’ to include information relevant to a small number of participants.

5.6.2. Utilising grounded theory methods strategies

The current study used IPA as the underlying methodology and its described data analysis methods. It was nevertheless helpful to utilise three additional strategies, drawn from grounded theory methods, to supplement IPA methods in the data analysis. Grounded theory methods, as developed by Glaser and Strauss in the 1960s, have been widely used within the area of health research. Grounded theory methods provide clear guidelines in regard to analysing qualitative data. The strategies of initial coding of the data, developing an analytical diagram, and constant-comparison were used in the present analysis to assist with identification of important themes in the data.

Charmaz (2000) describes the following strategies that help guide the data analysis.

1) Initial coding of the data

Initial coding helps to develop ideas and gain insights into participants’ views and experiences. This step helps the researcher to develop questions about the meaning one makes of the data. It correlates well with IPA’s strategy of looking for themes as it allows for their identification by examining each line of the transcripts and summarising significant responses.

2) Analytical diagram

Strauss and Corbin (1990 as cited in Charmaz, 2000) discuss the use of an analytical diagram to aid the coding process. The diagram highlights the different conditions that describe and/or affect the phenomenon, ranging from distance to close conditions. This matrix potentially helps in the development of explanations and predictions in regard to the studied phenomena. Developing and drawing a matrix of the emerging themes and subthemes was a useful tool in the second stage of the IPA data analysis (connecting the themes). As the analysis progressed it emerged that some themes and subthemes 'fitted' well in relation to more than one component of the evaluation. The matrix allowed for a closer look at how certain subthemes were linked and to aid in the decision process where they were placed as their content ended up being closer to one evaluation component compared to the other. Looking at the different themes and subthemes across the evaluation components and at each individual component through a matrix helped to gain a clearer picture of which themes to combine or to separate. It was particularly useful in regard to the content of the evaluation component of participants' experiences of the course as this aspect provided very diverse data. For example, while reading the transcripts initially the two themes, group teaching and social support, emerged. However, when looking closer at the data it became apparent that these two themes were not just linked but intertwined as participants talked about support they received to attend a group programme. As a result a combined larger theme of 'group teaching and support' emerged in the final analysis.

3) Constant-comparative method

This strategy was utilised during all three levels of data analysis. This initially meant comparing individuals' accounts across the initial interview and across time (between initial and follow-up interview), and tracking changes in regard to their experiences. At the third level of analysis it meant comparing participants' experiences with each other, comparing incidents (and participants' experiences and meanings they attached to these), comparing emerging categories, and finally comparing categories with each other (Charmaz, 2000).

The following four chapters report and discuss in detail the outcomes of the analysis. Each chapter focuses on one component of the evaluation, starting with participants' experiences of the course, followed by perceptions in regard to self-efficacy and quality

of life. The final analytical chapter focuses on new information gained at the 3-month follow-up interview. Each chapter is framed within a main theme that best reflects participants' accounts in regard to this specific component.

Summary

The current evaluation of a diabetes self-management programme recruited 7 participants for an initial face-to-face and a phone follow-up interview. IPA strategies were utilised in regard to sample size, homogeneity of the sample, participant involvement and interview structure (semi-structured). IPA suggestions in regard to data analysis are looking for themes, connecting the themes and continuing the analysis with other cases and these were used in the current study. Three analytic processes, developed for grounded theory research, were used to enhance data analysis. These were the initial coding of the data, the use of an analytical diagram and constant-comparative method. The combination of IPA strategies and grounded theory processes provided a structured framework for me to familiarise and immerse myself into the data in order to provide an authentic analysis and account of participants' experiences and perceptions.

Chapter 6 Participants' experiences of the course

or

“Six weeks sounded very long, but it was worth the time”

6.1. Introduction

This chapter is built on the descriptions of each participant's course experiences. A number of themes emerged during the interviews when participants talked about their views of the course. The themes that were identified in this part of the evaluation are:

- Finding out and deciding to enrol/attend
- Content of the course
- Group teaching and support
- Future participants

These themes arose due to their prevalence in the account of most, or often all, participants, providing rich information on how participants viewed the course. The themes will be defined and discussed in more detail and linkages between themes (where applicable) will also be explained.

6.2. Finding out and deciding to enrol/attend

During the first two initial interviews participants mentioned, on a number of occasions, who told them about the course. Because this appeared to be of importance to the participants, subsequent participants were asked questions regarding this topic if they failed to bring it up themselves during the course of the interview. Participants mentioned on numerous occasions the time frame that the course involved, as well as the time and day that the course was to be held, and how this impacted on their decisions to attend. Participants made continuous references throughout the interviews as to why they decided not to attend all of the course sessions and how they felt about missing out on some.

6.2.1. Finding out about the course

A number of different people discussed or suggested the option of attending the course with the individual participants. These included practice nurses, the general practitioner, diabetes nurses and Care Plus nurses. Participants saw the provision of information about the course as part of their relationship with their health provider.

Participants pointed out that being told that “the course was worth going to” (P3) made them feel “that I had a good rapport with my doctor” (P7) or nurse, and that they received good advice and care. Others felt that the opportunity of attending the course was valuable itself and the course might allow them to “learn everything I can about it (diabetes)” (P2).

6.2.2. Deciding to enrol

A key consideration for participants when deciding whether to enrol in the course was the time when the course was to take place. Decisions in regard to attendance were based around the time of day - “yes, it was early (in the morning)” (P4) - and whether it fitted around work commitments, like having the day off work. “I actually found it quite the right time” and “it was very convenient” (P5). Participants reported that they “may not have gone because six (days of missing work) is quite a bit” (P1) if the course had been at a different time or day.

6.2.3. Length of course and each session

Participants also talked about how the information that the course would go over a period of six weeks, with each session lasting two and a half hours, impacted on their decision to attend. One participant described the experience of receiving that information as follows: “Well, when I first got the paper I thought holy shit six weeks?” (P2) and another participant also wondered “how on earth are we going to fill-up two and a half hours for six weeks?” (P3). However, participants thought it was important to point out that in hindsight these concerns were unfounded and that the course length was certainly appropriate. Participants’ comments here ranged from the 6 weeks itself as in: “it is amazing how quickly it went really” (P4) and “no I don’t feel that its way too long” (P5) to the 2 ½ for each session: “but we did (fill up the hours)” (P3) and “possibly is the max, two and a half hours, if you had it too long you (would) sort of probably find it memory loss” (P1). One participant added: “I think (that if you) ask everybody they would have wanted it to go on a bit more” (P2).

6.2.4. Specific reasons for non-attendance of some sessions

A number of participants did not attend all sessions but made it very clear during the course of the interview that this did not have anything to do with a lack of interest in the content of the sessions but was for other reasons. A number of participants did not

attend a specific session (such as the supermarket tour) because they had recently attended a similar tour and did not feel the need to go again. P6 explained it as: “the only one that I didn’t attend was actually the supermarket one ‘cause I’ve been”.

Other reasons that participants believed had prevented them from attending specific sessions were family commitments: “I had to leave that day I was so annoyed...I was really frustrated that I missed that” (P3), or medical reasons: “I had health problems” (P4). One participant mentioned that the leaflet providing a weekly overview was very helpful because the participant “only came a few times” due to other commitments but was able to choose the sessions “that I wanted to go to” (P7).

6.3. Content of the course

All participants reported that the course was worth going to or that “the information that I got I felt was excellent” (P7). Participants reported that it had been worth being “able to come each and every time” (P1), because, through the course, “I learned from them how to look after myself” (P5).

6.3.1. Contents that were liked

When questioned, most participants initially reported that they liked the content of all the sessions. “I liked every bit of the thing” (P5) and it “was all positive” (P4). As one participant summarised: “it was all dealt with, it didn’t go on and on and on” (P2).

When it came to the actual content that the participants thought was most beneficial a broad range of answers was provided. Participants reported that the most useful information was in regard to healthy eating in general and about reading labels and portion size in particular. For example, some participants thought the course helped them to learn how to “manage your diet” (P2) and about “changing my diet” (P5).

Learning how to read food labels properly was a specific aspect that participants thought they benefited from in regard to making changes towards healthier eating. It raised awareness of what is in the food as expressed by P4: “no, you got to read. I used to be one of those that would go around, yes we needed some and bang, bang, bang into the trolley and you didn’t look”. Participants felt that it helped them make better choices in regard to food that they know: “I still read the labels” (P2), and in regard to

new products that come on the market: “read labels, read labels, read labels...sometimes new ones come on the market and you like to try them...so I can regulate as to what gets eaten” (P3).

Portion size was the other aspect of the course that participants felt they benefited from a lot. I noticed that a number of participants when talking about portion sizes used their hand as a reference guide as well to underline that they now knew the right size. As participants stated, the information helped to raise a “bit more awareness with the volume of intake” (P1), the “quantity...and the size and I’ve got a small palm” (P4).

Five of the participants also found the session in regard to causes of diabetes very beneficial and these participants referred specifically to the ‘bodylink’ (a teaching tool) as helping them understand what is happening inside their body. The participants added they found out “even how the body worked” (P1), that “I was quite interested in the flat body...all the working parts...aware we had a pancreas but I didn’t know really how much it worked and what its functions were. I’m a lot clearer on that now” (P4). The appeal of the ‘bodylink’, as one participant put it, was that “it is all visual” (P6) and that with the “model...showed us where the glucose went” (P3).

Participants mentioned that the information in regard to the blood tests was very useful to them. Participants specifically talked about the tests they did themselves, but also thought that they now understood what the ones undertaken by the laboratory were for. Participants liked the fact that the course helped them to understand the “significance of the blood tests” (P7), “what your blood tests do... and also when to test and how often to test” (P2).

Individual participants mentioned that they benefited from information in regard to foot treatment, medication, sick day treatment, green prescriptions/exercise, psychological aspects of diabetes (impact of stress and depression) and support groups available in the community.

6.3.2. Contents that were disliked

Initially all participants responded that there was nothing about the course that they did not like. However, as the interviews continued most participants talked about certain

aspects of the course content that they would like to see improved or changed in some way.

Two participants suggested that insulin should not be included in the course, seeing the people that attended (at least in this instance) were not injecting insulin at this stage and that the thought that this would happen to them was more of a shock than useful information at this stage. “They said that everybody that has Type 2 diabetes ends up on insulin... I don’t think that was really nice...it was a real shocker” (P2) and another participant went on to say that “I found it depressing...like it was just a downhill until you hit insulin” (P3).

Finally, another aspect that participants felt could be better explained was the difference between Type 1 and Type 2 diabetes, seeing as one participant reported that “somebody has worried me since I’m Type 2 and they tried to tell me it can turn into Type 1” (P4) and two participants asked during the interview “when does a Type 2 become a Type 1?”(P3).

6.4. Group teaching and support

Most participants mentioned at some stage the positive aspects of group teaching, the number of people that attended the course and how they felt that facilitated interaction among staff and members of the group.

6.4.1. Group size

Most participants mentioned the group size and that they felt starting with a group size of eight and a maximum of 12 was excellent. “Yeah eight is a good size even 12” (P5) or as another participant pointed out: “Originally eight or nine? I felt that was a good number” (P6). Participants also talked about the fact that some people dropped out after one or two sessions. Participants pointed out that while this might have been unfortunate for those people “they probably had different reasons why they didn’t come back” (P4) it was positive for the ones that remained seeing it “did make it seem like luxury education” (P1).

6.4.2. Benefits from group course

All participants spoke about the benefits they received from attending the course. These benefits included learning from staff and also meeting, learning and sharing information with other people with diabetes

6.4.2.1. Impact of other participants on the course

Participants mentioned the positive aspect of meeting people that have similar experiences and being able to share them. “It was an interesting group...and the interplay between them” (P7). One participant felt that it was “Worth my time going to meet other people with another psyche but similar problems and that” (P1). Another participant added the course allowed to “share thoughts with other people...how they are coping, how they are managing, how they are not managing” (P3). Participants also talked about the fact that the course provided some social support. “The course gave you company” (P4).

Participants thought it was very beneficial that people attending the course ranged from ones that had been newly diagnosed to ones that had been diagnosed some time ago; this allowed for comparisons between themselves and others. “It was beneficial and even the fact that there were people from all different walks of life that were there for different reasons and in different stages” (P4). Participant that had been diagnosed at an earlier stage felt that they could “understand where they are” (P7), i.e. the recently diagnosed participants. Participants also felt that this allowed for a better understanding of where they themselves were in regard to their diabetes seeing “you are never quite sure where you are at, but you are somewhere along that continuum” (P7). At the same time recently diagnosed participants felt that they could learn “from each other at the same time” and taking away information and support not only from staff but “some of the things that the guys said on the course” (P6).

Participants felt that as the course progressed it did not only become easier to talk to each other but that there was also enough time during each session that allowed for conversations. “As the course progressed everybody sort of loosened up and relaxed a bit and got more talkative and asked questions” (P3). Participants mentioned that as the course progressed they felt they could “freely talk” (P1) to each other and that by doing so they felt better “when you talk about it and you feel free” (P5).

6.4.2.2. Impact of staff

Participants found that they benefited from having a number of staff facilitating the course, seeing each staff member had a different type of expertise. They felt that the staff “knew what they are doing” (P4) and that “it was good having the different rather than having the one speaker” (P2). As one participant put it “you may as well learn from the best” (P2); the health professionals that have the experience and the knowledge in regard to diabetes compared to other people that are trying to give advice.

Participants felt that it was important that the staff were easy to talk to. That made most more comfortable to openly ask questions and provided a good atmosphere. They were “capable staff that could relate to people” (P1) and were “very helpful” (P5).

6.5. Future participants

Most participants talked about some improvements to the overall course during the interviews. Participants talked about recruiting participants for future courses, the inclusion of a Māori staff member, specific changes to the content of the course and a follow-up session for themselves.

6.5.1. Recruiting new participants for the course

Most participants talked about different options of recruiting future participants. The main suggestions were talking to family and friends (particularly ones with diabetes) about their experience, recommending the course to others and increasing advertising.

Some participants mentioned that they had talked to friends, people at work and complete strangers about the existence of the course. One participant mentioned that while at the chemist “there was a lady in there she just found out that she had diabetes and I said well I recommend this course highly” (P3).

All participants mentioned that they had talked about the course content with their family and friends. The information reported to others was very diverse, ranging from general information (easy access, no cost) to specific practical information (tips on dealing with special occasions, avoiding long-term complications and controlling diabetes). Participants also told others how they personally benefited from the course,

which ranged from the positive impact the course had on newly diagnosed people to one's general well being. Participants emphasised the importance of talking about all aspects in regard to diabetes self-management, as this helped them to educate others, especially their family members. As one participant put it: "Because it just doesn't do with diet" (P2).

6.5.2. Increasing future Māori attendance

A number of participants (Māori and non-Māori) expressed their surprise and concern that only a small number of participants were Māori. "It was unfortunate that they were not more Māori... maybe they are shy" (P1). Participants' main suggestion in regard to improving numbers of Māori participants in future courses was the inclusion of "a Māori person like a Māori doctor or Māori nurse" (P6). Participants felt this would allow for the teaching of "a Māori perspective about things in the management course" (P5).

6.5.3. Improving content of the course

Participants had very different ideas when it came to improving aspects of the course itself. Suggestions here were in some ways more personal compared to other aspects. Improvements mentioned focused on issues around asking questions, improvements to teaching tools, handouts and medication awareness.

In general, participants felt that while they could ask questions at any time, it would be good to also have some time where they could privately ask questions that would not be answered publicly. As one participant described it: "Because you see that was a question I would have asked" and adds "didn't feel comfortable because it would have been a public question".

Another improvement participants talked about was the continued inclusion throughout the course of certain teaching tools, especially the body link as participants felt that this helped them to understand what was going on in their body. Participants also talked about the numerous handouts they took home with them. As one participant described it: "the more notes there are around the less important each one becomes" (P2). A suggestion that was made was to "colour code them" by dividing the information into basic information, advanced information and information provided by other groups.

Participants felt that this would provide them with a better reference tool once the course had finished.

Finally, the session on medication provided a number of responses and reactions from participants. Participants felt that the information was necessary to get a more realistic picture of what could happen in the future, but suggested that the information in regard to oral medication should include more information when one has to start taking these. As one participant pointed out it is “better to be aware about it” (P1) and another one added that it would help “to find out at what stage do you go on medication” (P3). The session also elicited strong responses on the issue of starting on insulin one day. While participants thought it was important to receive some basic information, they felt it would be better if a separate course would be offered “about insulin for insulin people” (P2).

6.5.4. Future meeting for participants of the current course

Participants expressed the wish for an annual follow-up session for the people on their course. When questioned about potential content of the course, participants thought that it could be used to receive updates on latest information in regard to diabetes in general and more detailed information in regard to specific topics (like oral medication and insulin). This information was seen as having two purposes, to receive the latest information themselves and to use it to educate others with diabetes. Participants felt that the follow-up session would provide them with the opportunity to catch-up with the other participants, exchange experiences and support each other.

Summary

Participants were informed about the programme through various sources and their decision to enrol was based on recommendations and the time of the course. While participants reported that the length of the course sounded too long initially, this opinion changed once it started. All participants emphasised that the course was worth their time and that they benefited from the topics discussed and the good group size. Participants appreciated having different experts and that people with diabetes ranged from newly diagnosed to diagnosed years ago. Participants recommended some improvements to the overall programme. The provided suggestions focused on improving participant recruitment through different forms of advertising, having a

Māori staff member to increase Māori participation and modifying some content.

Participants mentioned that the introduction of follow-up sessions would be beneficial.

Chapter 7: Perceptions of participants in regard to their self-efficacy or

“I know what I need to do and I’m confident to do it”

7.1. Introduction

The main focus of this chapter is on participants’ perceptions in regard to their self-efficacy when it comes to initiating and maintaining diabetes-related behaviours. When participants talked about self-efficacy they generally referred to confidence and the course’s impact on their confidence. All of the participants linked confidence with the theme ‘knowledge’ and discussed how their confidence improved through the knowledge they in some way gained from the course.

The following themes were raised by all or most participants in regard to self-efficacy:

- Knowledge
- Confidence of being in control of own life
- Confidence to initiate diabetes-related behaviours
- Confidence to educate others
- Confidence to maintain behaviours in the future
- Confidence to find help/support in the community

Participants who classified themselves as ‘newly diagnosed’ specifically raised another theme that will be discussed in this chapter. I find it important to highlight this theme, as it played a role in the lives of newly diagnosed participants, a subgroup of participants in the overall course. The theme that arose from the interviews with newly diagnosed participants specifically is:

- Confirmation of having diabetes by attending the course

Finally, individual participants talked about other aspects relating to their diabetes in which they gained more confidence since attending the course. These will be discussed under the heading:

- Individual participants

7.2. Knowledge

All participants reported that they gained new information and knowledge by participating in the self-management programme. Participants that had been diagnosed with diabetes for a longer period of time also reported that they were able to refresh and confirm information and knowledge gained prior to the course. This knowledge pertained to all aspects of diabetes-related behaviours, with a specific emphasis on the topics regarding healthy eating and physical activity.

7.2.1. New information and knowledge

Some participants talked about the fact that all of the information they received during the course was new to them. This helped them to feel they could make the right changes to their lifestyle and their diabetes-related behaviours. One participant summarised this as: “All the things, which I learned from the course...are new” (P5).

The same participant, representative of others, mentioned receiving extensive information at the initial diagnosis, especially in regard to healthy eating. This previous information was viewed as not as helpful and rather overwhelming at that stage. Even though the information was available in regard to portion size and label reading, the participant didn't know how to apply it: “because I don't know how to eat” (P5). Attending the course therefore provided the practical application and clarification of previously received theoretical information.

Some participants that had been living with diabetes for a number of years before they attended the course also felt that they received new information and had benefited from this. As one participant summarised it, the course provided the “hard facts” (P7).

When participants talked about gaining new information and knowledge they eventually linked this with confidence. One participant felt that the new knowledge gained allowed them to “balance it up”. This meant comparing what the participant was already doing and what the course leaders recommended in regard to successful diabetes self-management. This comparison helped the participant to realise that “I must be doing alright” (P6), in regard to the different areas of diabetes self-management. The newly acquired information did not lead to behavioural changes but raised the confidence in regard to the previously initiated diabetes self-management behaviours.

Another participant linked gaining new knowledge with a greater understanding of what was happening to them, their body and their health. “If you can have a bit of knowledge you can treat your (self), not treat yourself but understand a lot more” (P2). Participants related that knowledge back to other aspects of diabetes-related behaviours, the purpose of their medication and blood glucose monitoring. P2 talked about now knowing the “benefits of the pills” and that this, for example, helped the participant in regard to eating treats. “I know that I can do that safely if I want (a specific treat)” (P2). One participant initially talked about the link between blood glucose monitoring and how it reflects on how well you are controlling your diabetes (and preventing long-term complications) but went on to include “all the sorts of everyday things that happen to you, so you can monitor yourself or you can know how you are going” (P7).

7.2.2. Confirming information and existing knowledge

This was an important theme that was raised by the participants that had been diagnosed at least a period of months, if not years, before attending the course. Participants felt that they had accumulated vast information in regard to dealing and living with their diabetes since diagnosis. They added, however, that attending the course was nevertheless beneficial as it helped to confirm their previous knowledge in different ways.

For some participants the main benefit was that it confirmed their established routine was how it should be or in need of only minor adjustments. One participant described this as the course giving “you confidence that what you are doing is not far off the track” (P1). Another participant added that the information from the course “made me check that I was doing sufficient positive things, (it) gave me a benchmark” (P7).

Other participants mentioned that the course allowed them to reconfirm existing information. One participant described this as “just to refresh yourself” in regard to the information (P3), while another participant added that “it dotted the i’s and crossed the t’s ” (P7). A third participant emphasised that refreshing your own knowledge was important, as one might become too complacent with the routine until illness or complications appear. “I think you need to be refreshed. It is no good just sailing on...until you feel really crook” (P1).

7.3. Confidence of being in control of own life

This was probably the most important theme that arose during the interviews in regard to self-efficacy. Participants felt that the knowledge they received provided them with the confidence to be in control of their own life, not only at this stage in their life, but in regard to their future as well. Participants talked about using the information at the course that was important to them to handle their self-management behaviours “so that they become part of my life and almost instinctive so I don’t have to think” (P7).

Another participant added that: “you feel more confident I think in understanding things. It just sort of fits in your brain and it filters out...as the day goes” (P1).

7.4. Confidence to initiate diabetes-related behaviours

All participants talked about an increase in confidence when it came to initiating a wide range of diabetes-related behaviours. As one participant summarised it: “You have to be in that frame of mind before you can actually do it” (P6). One participant, before providing specific examples of initiating diabetes-related behaviours, talked about the process of deciding on which aspects to initiate and incorporate into one’s life. The participant described this as follows: “ I have certain things that I have decided that are important for me to handle... they become part of my life...so I don’t have to think (about them anymore)” (P7).

Specific aspects of initiating diabetes-related behaviours centred to a large extent around changes to eating habits, as one participant said: “my goodness I’m conscious now” (P4), while another added: “I feel confident that I can manage my own diet” (P2). Other aspects included “reading labels...and I just feel really confident” (P2) and taking up physical activity, or as participants described it: “sort of get moving and also losing the weight” (P2) and “it is supposed to be good for you I think” (P1).

7.5. Confidence to educate others

Different lines of thinking emerged when participants talked about this theme. While participants agreed that the course helped them to get the confidence to educate other people, the education itself was used in different ways. For some participants the course helped them to educate their partners, who couldn’t attend the course. to ensure

that their partners had a similar level of knowledge and understanding in regard to diabetes self-management.

For other participants the course provided the necessary knowledge and confidence to educate others (especially family and friends) who had previously been trying to educate the person with diabetes on what they supposedly were and were not allowed to do. “A lot of people try...and they think they know more than what you actually do” (P2). In these instances participants felt that they were better equipped to deal with advice that they did not wish to receive or was inappropriate. Participants felt that they were more confident in telling ‘well meaning’ people that they did not need to be on a special diet and that they could “eat anything” (P2). The participant added that this included telling friends that they did not need to change a planned meal or cook something special for the participant.

The third aspect in regard to confidence in educating others was actually using the knowledge and then to passing this information on to “a lot of other people”(P2). These others mentioned by the participants included family members, friends, colleagues, clients, members of groups and clubs they attend, and even strangers.

7.6. Confidence to maintain behaviours in the future

An important aspect of this theme for participants was the fact that they had to set achievable goals and believe that they can maintain the behaviours. As one participant put it “ you can never do perfect and you set yourself a goal that is reasonable” (P7). Participants mentioned that while feeling confident to change behaviours was one aspect, the risk of actually changing too much at once could be high. They discussed that the thought of overdoing it and not being able to maintain the behaviours had crossed their minds but they felt they solved this by slowly initiating and building up diabetes-related behaviours. One participant summarised it by saying: “if you are going to too much trouble you won’t carry it on anyway after a while” (P7).

Participants talked about the confidence that they now had to continue their more or less established behaviours in the future seeing “it is for your own good” (P4) and another participant concluded, “I’m in charge of the ship, sort of thing” (P2). Participants also made specific references in regard to certain aspect of diabetes-related behaviours that

they felt especially confident to maintain over time. The aspect that was mentioned the most was healthy eating “I feel confident that I can manage my own diet” (P2).

Another participant emphasised that physical activity was another important aspect of living a healthy life and that the participant felt “very confident, very confident (in) keeping up with the exercise”(P3). A third participant talked about the importance of maintaining the behaviours in the future but at the same time having the confidence to manage sick days (feeling unwell due to diabetes) should they arise in the future. “(It is important knowing) what you do when you have a hiccup in your health for a day...it (the information) is all in the back of my mind (now)” (P1).

Another aspect that emerged was confidence in regard to blood testing. Newly diagnosed participants talked about how the course raised their confidence to start testing or to increase the testing - “I finally got to do them”(P4) - or how the course provided them with the confidence that they were testing often enough: “I’m not changing it”(P5). Some participants talked about how they tested quite often, after their initial diagnosis, but now, with the knowledge and confidence gained, felt that they could decrease the testing and “don’t worry about it too much”(P3).

7.7. Confidence to use help/support in the community

This theme was also discussed by a number of participants. Participants felt that the course provided them with the knowledge of what kind of professionals and organisations were providing support in the community and how one can contact them. As one participant pointed out “basically I feel more confident that I know that there are people out there that can help you” (P6)

A related aspect of this theme also emerged during the interviews, which was communication with the participants’ main health professionals (GP or practice nurse). Participants felt that they were more confident in regard to where their blood levels should be and were able to discuss this aspect with their GP. One participant described it as, the “...(GP) never told me what it should be, what level” and the participant went on to say that the course provided the knowledge that if the GP said that a test was fine, they would now know and be able to comment that “it (the blood level) was too high for me”(P5).

7.8. Confirmation of having diabetes by attending the course

The following theme was specifically raised and appeared to be particularly important to participants that classified themselves as newly diagnosed. It appears that the course, while aimed at all people with Type 2 diabetes, had the added benefit of confirming the diagnosis to members of this subgroup. This theme came as a surprise to me as I had not anticipated that participants diagnosed with Type 2 diabetes would use the course as a way of confirming that they had diabetes.

Newly diagnosed participants talked about initially not believing the diagnosis of diabetes “I wasn’t accepting that I had diabetes” (P6). One participant pointed out that the course helped “to ground myself” in regard to believing and accepting that they had diabetes. Another participant added that attending the course was their way of confirming that they did not have diabetes, but at the most might be “borderline” (P4). This participant later on added, “I didn’t think I had any cause to come” but then stated that it was “beneficial”, as they realised that they did indeed have diabetes.

Participants felt that once the course started they received a lot of information in regard to “things I was supposed to do” (P4) but also “good support” and an understanding of “what is diabetes” (P6). This understanding helped to confirm that they actually had diabetes because the information provided, particularly in regard to symptoms, fitted their experiences. Another participant added that associates had started telling the person what they should be doing, and “you’re not going to do it when people keep telling you what to do” (P2). The decision to attend the course was therefore initially a counter reaction - “and that’s why I thought well I do this course” (P2) - to the unwelcome advice.

7.9. Individual participants

7.9.1. Confidence to prevent long-term complications

A small number of participants talked about the course providing them with knowledge, the tools to control, and the confidence to prevent long-term complications “you can prevent that happening” (P3). Participants believed that “with the feet and the glasses, (referring to possible complications) if you control you’ll be right” (P2) and that “I know how I can look after myself, that is the main thing and I’m not worried” (P5).

7.9.2. Confidence to be assertive when eating out

Two participants talked about how the course helped to raise awareness of what kind of food, and also what portion sizes, were offered to people when eating out. One participant explained that before the course “I would have never been really conscious of that” (P4). The same participant later on added that the course helped to increase confidence to complain that the menu didn’t provide enough healthy eating choices and that the portion sizes were too large “but I did have to say (something to the staff at the restaurant)...because the only thing that I could see that I could have...and I knew it was going to be too big”. At a later stage during the interview a solution was discussed when the participant added that “you go find somewhere where you can eat” and that the participant now had the confidence to look at the menu and leave if not satisfied with the options.

Summary

Participants reported that the course increased or confirmed their existing knowledge, which helped them to gain confidence in regard to different aspects of diabetes self-management. Participants mentioned that they felt more confident when it came to initiating and maintaining diabetes-related behaviours, especially in the areas of healthy eating and physical activity. Participants also felt more confident when it came to being in control of their life, in regard to educating other people when it comes to diabetes and diabetes self-management and also where to find help/support in the community. For newly diagnosed participants the course had an added benefit in that attending helped them to confirm that they had diabetes. Some participants also pointed out that the course increased their confidence in regard to preventing long-term complications and to eating out. Overall, it appears that the course, through providing relevant information, helped to increase participants’ self-efficacy.

Chapter 8: Participants' perceptions in regard to their quality of life or “Life is good, diabetes is just another thing to handle”

8.1. Introduction

The focus of this chapter is on participants' perceptions in regard to their quality of life. A main aspect for participants was how diabetes self-management and attending the diabetes course impacted positively or negatively on their life. As the individual interviews progressed it became apparent that actual behaviour changes played an important role in participants' assessment of the status of their current quality of life.

Participants used comparisons between themselves and others (with diabetes or other illnesses) as one way of assessing how well they are doing. Most participants reflected back on how they felt when initially diagnosed with diabetes and now, using this as another form of assessment. Participants discussed family support, its impact on their life and their dealings with it. Some participants mentioned negative aspects of having and living with diabetes, while at the same time describing strategies to achieve a more positive outcome.

The following themes will be discussed in more detail in the current chapter:

- Behaviour changes
- Comparison with other people with diabetes
- Comparison with people with other illnesses
- The importance of support
- Dealing with the 'food police'
- 'It is okay to have treats'
- Future outlook on life
- Negative aspects of having diabetes
- Looking back at diagnosis

8.2. Behaviour changes

For most participants this was an important aspect when assessing their current health and quality of life status. Participants reported that having diabetes encouraged them to

implement behaviour changes reflecting good diabetes self-management. Behaviour changes in general were seen as something positive to improve overall health. Most participants mentioned that these changes were now part of their daily routine and that they had overall positive effects on their life and their future outlook.

Behaviour changes were reported in different areas of diabetes-related behaviours. Changes to eating behaviour and physical activity outranked most other changes. It appears that the diabetes self-management programme helped participants gain confidence (as discussed in the previous chapter) in regard to initiating as well as implementing and maintaining changes.

One participant described the changes to physical activity as follows: “(I) do a walk...now it has not been something that I really wanted, loved but it has been good for me”(P7). The participant continued: “knowing that I’m diabetic has made me take it (walking) up again and I feel a lot more healthier for it” (P7).

Other participants talked about the different physical activity options that they were utilising now. These included Green Prescription, attending the gym and going swimming. One participant described the experience of starting up physical activity as: “something (that I thought) I had to do. (I) didn’t realise, you know, I could please myself (by participating in physical activity), so I went along and did it and it has been good for me” (P4).

All participants provided specific examples when discussing the implementation of a healthier eating routine. All participants related the changes back to information received while attending the programme. The areas in which participants made changes were varied. For some participants changes meant “making more (food) myself” (P1) and eating more “veggies, the fruit...and the cereals” (P6) instead of buying ready-made foods. Other participants reported an increase in reading labels when shopping and, through that, changing the food that they buy. Most participants talked about the importance of reducing portion sizes. As one participant summed it up: (the main aspect is to reduce the) “quantity...and I’ve got a small palm” (P4), thereby applying information learned during the programme.

Once the healthy eating changes were implemented and part of a new routine, participants reported that they started to lose weight. “My loss would be about six kilogram” (P1); or as another participant summarised it: “I never felt I was really overweight but I lost one stone and feeling better for it, I must admit” (P4). Participants highlighted the importance of the link between reading labels, weight loss and diabetes control. One participant talked about setting priorities, putting diabetes control over weight loss, and stated that reading labels played an important role in achieving this. “What is your priority? You got to control. Control your diabetes then work on your diet (and) losing weight. Cause I think that is more important” (P2).

8.3. Comparison with other people with diabetes

When assessing how well they are doing, all participants mentioned other people with diabetes. Overall, participants felt that they did much better and that they had it ‘easier’ compared to other people with diabetes. As P1 described it: “It (Type 2 diabetes) didn’t worry me at all...my (relative) got up to the injectable period...that was an experience”. Another participant added “a friend (with) Type 1 injects 6,7,8 times a day...I thought well...if I manage right I’ll be sweet” (P2). A third participant talked about a friend who “had his leg amputated (due to long-term complications of diabetes)...so I know the horrible side of it (diabetes)...I just don’t want to go there” (P3).

One participant remembered that “I know a couple of people that have actually died of diabetes...and that is what I thought diabetes is all about” (P6) but the participant later on explained that “it is not (the case)...we are educated (to control diabetes)” (P6). Finally, for another participant the reminders of what could happen if diabetes is not well controlled were very personal. The participant kept “thinking about my mum, about my grandmother, how they died...I don’t want to go through this situation” (P5).

Participants benefited from the fact that all people attending the programme had Type 2 diabetes and were not injecting insulin. Making comparisons between oneself and the other course members helped participants to gauge how well they were doing. As one participant pointed out the “meeting of other people and seeing how they handled things was a big plus” (P7). Another participant added, “it was beneficial (meeting the other) people...that were there for different reasons and in different stages” (P4). One

participant further explained this by saying: “these different people around you...(I) become more aware (of how well I am doing)...you balance it up...(and reach the conclusion) I must be doing all right” (P6).

8.4. Comparison with people with other illnesses

Participants compared their living with diabetes to people having to live with other chronic or terminal illnesses. While their circumstances might be initially viewed as negative, when compared to others they were still ‘better off’. Participants described as diabetes having a relatively small impact in their life. The comparisons resulted in a greater determination to live their life in a positive way. P2 described living with diabetes compared to other illnesses as: “Hello, I haven’t been given a death sentence...I’ve only just got Type 2 diabetes...So that’s why I thought let’s get on with (life)”. One participant talked about “(I’m) not going to let that (having diabetes) beat me and I have seen people even with cancers...and they are still going” (P1).

8.5. The importance of support

Participants talked about the importance of receiving support and having people in their life that they can share their experiences with. The participants received social support from a number of sources but family and friends were the main sources and most widely discussed. When talking about their quality of life participants linked this to their relationships with family and friends.

Participants talked about their own family as being a good support system for them. Most participants thought that being able to talk about their experience of having and living with diabetes impacted positively on their life. Participants reported that family members helped them to deal with diabetes in general. As one participant noted: “I had my children” (P1). Another participant added: “it makes a difference when you have a partner who understands, who will listen und who is supportive” (P7).

Participants, knowing that they have family support, felt motivated to continue their routine. As one participant mentioned: “it makes it all worthwhile” (P7) and another participant added: “I got too much living to do (and spending time with family)” (P3). Another participant described positive reactions from various family members in regard

to the lifestyle changes as: “they said it is good, especially when I’m a diabetic person” (P5).

Family members were seen as being helpful in regard to the more practical aspects of diabetes-related behaviours. These aspects included providing healthy food, participating in physical activity and helping with blood testing. As one participant pointed out: “(my family) do cater for me (by providing healthier food options) when I turn up” (P4).

Time with friends was often linked to eating or eating out. Participants had mixed feelings in regard to this topic. Some participants felt that they were eating healthier when eating with friends compared to eating alone. P1 thought that: “if you eat by yourself you don’t eat as good”. Participants talked about friends being worried and offering to prepare special food for the participant. One participant was able to explain to friends: “that (I) can eat everything and it doesn’t really worry me” (P2), hence making it easier for everybody while enjoying the company of friends.

For most participants social events that involved meals were still seen as something positive, with them either viewing it as a treat or being selective with what they ate. However, some participants pointed out that since being diagnosed with diabetes, attending certain regular social events had become more difficult. As these instances could not be classified as ‘treats’, participants were weighing up if it was still worth their time attending. During the initial interview one participant described the dilemma as follows: “There is a lot of the social things that I might have been involved in that I can’t be bothered with now...I mean what’s the use (of attending) for me? Well I would have to take my own food” (P4).

Participants had mixed opinions in regard to the advantages or disadvantages to preparing healthy food options when other family members (that did not have diabetes) lived at home versus the person living on their own. As one participant pointed out: “I find it harder to eat alone because (it is) much easier to cook for more (people)” (P1). Another participant echoed this: “with the kids...moved out, well I suppose it was easier (before) cause I would cook a whole lot” (P2). While another participant had a completely contradictory viewpoint: “it must be hard if you (have) a family” (P4).

8.6. Dealing with the 'food police'

'Food police' was a term used by the course leaders to describe family members or friends that are watching over participants' food consumption to the point of being overbearing. Most participants could spontaneously identify at least one family member that they felt fitted that category. These could include partners, children, and friends.

When it came to dealing with the 'food police' participants mentioned different strategies that they now used having attended the course. This included telling people "I have done a 6 week course" (P3) or "I've been there got a certificate for that" (P2), implying that therefore they had the better information to deal with their diabetes in general and healthy eating in particular. Other participants talked about accepting it as the time spent with that person was minimal: "it is only for a day or two" (P1).

8.7. 'It is okay to have treats'

While following most aspects in regard to healthy eating, participants thought that it was still important to "feel happy in yourself when you eat food (and not to) go overboard" (P1). This meant for participants to have the occasional treat as they felt that their life was better for it. One participant talked about weighing up the choices. "I'm well able to keep within my goals (in regard to healthy eating) and the goals that have been set (therefore) I could have a bit of that (treat)" (P7). Or as another participant described it: "you've got to have some enjoyment" (P2).

Participants talked about the decision making-process in regard to keeping their so-called 'treats'. Participants provided comparisons, pointing out that their type of treat was moderate compared to alternatives. One participant summarised it as: "The only thing I haven't really given up is...my glass of wine, but (I) don't line up the ice-cream barrel" (P4).

Participants felt that treats had to be placed within the bigger picture of all the positive changes that they had implemented since attending the self-management programme. One participant realised during the initial interview that while talking about the treats as something negative, they were after all only treats. The participant concluded that it

was acceptable to “(eat a treat), probably once a week. (It is all about) getting it into the right perspective” (P6).

8.8. Being in control of own life

This theme arose out of discussions surrounding participants’ future outlook on life. All participants talked about how they viewed their future. In general they described it in very positive terms. They thought they had the knowledge and confidence to control their own life and their diabetes. One participant realised that no matter what advice other people provided “the only one that can do anything about it is me” (P2). When questioned about their future outlook participants’ responses mirrored their feelings in regard to their life and the knowledge they possessed. P1 said: “I’m not too worried (and) positive about the future”. Other participants added that they had “ways of controlling diabetes” (P6) and were able to “monitor yourself” (P7).

Participants added that the course helped them to realise that “you can live a fulfilled life. They (course leaders) said (that) you can manage it, you’ll be alright” (P6). Overall, as one participant pointed out: “the course made me more determined to keep control of my life” (P3). A second participant added that taking control didn’t just mean making changes to one’s diet, but rather “it is a lifestyle change” (P2).

8.9. Negative aspects of having diabetes

The main aspects participants raised were concerns in regard to fluctuations of blood glucose levels and dealing with their diabetes during an illness. Participants talked about noticing when their levels were up: “I feel a little bit off” (P1), “I get this really hot feeling” (P2) or “I get a thumping headache” (P3). This had initially been worrying for participants, as they did not relate these symptoms to their diabetes. Over time, as they started to relate these symptoms to changes in blood glucose levels, participants learned what measures to take to avoid this from happening or at least dealing with it.

Participants were questioned about the impact of the topics of the self-management programme on their quality of life. Most participants named specific topics that had a negative impact on their life in general. The topics mentioned were developing long-term complications, progression of diabetes despite keeping good control and the possibility of having to inject insulin in the future.

Participants dealt with this information and their reactions in different ways. Some participants felt that it was important to receive all necessary information and deal with it. “If there (are) facts you got to accept them, otherwise you are hitting your head on a brick wall” (P1). This participant later added when it came to dealing with this negative information “you got to weigh up whether it is worth it (and it is) better to know about it” (P1). For a number of participants the information that “everybody that has Type 2 diabetes ends up on insulin” (P2) came as a “reality check” (P2) or “wake-up call” (P3).

Participants reported that the negative impact of this information, while initially discouraging, was short-term. As one participant put it: “(the information was) depressing...no matter how good you keep your glucose levels you still going to end up on insulin” (P3). However, as they continued talking about the information it did not deter them from “doing all I can (and making) sure it doesn’t happen to me” (P3)

Some participants talked about a lack of understanding on the part of some family members and friends as impacting negatively on their quality of life. It appears that some family members and friends did not make an effort to understand what it meant for them to live with diabetes. Participants reported that trying to explain what was happening did not seem to make a difference. As P3 mentioned: “(relative) doesn’t understand the effects, you know that it (diabetes) can have and well I have trouble getting through (to the person).”

Two participants talked about feelings of guilt when it came to their diabetes-related behaviours. For one participant this was related to the concern of potentially falling “back into those (old) habits (before attending the programme)” (P6). The second participant related it to the concern “that you are not doing enough things” (P7). Both resolved their concerns by taking a closer look at their actual diabetes-related behaviours, comparing them to the recommendations, looking at their test results and reaching the conclusion that they were doing fine. P7 also discussed the established routine with a health professional and was told that everything was well. “I thought, right, that is good” (P7).

8.10. Looking back at diagnosis

During the interview most participants reflected back on receiving the diagnosis of diabetes. These participants described the diagnosis as a ‘shock’. One participant described the feeling as: “well I thought I’ve got diabetes, that is it” (P2) and another added: “it was tough for starter” (P5). Especially participants without a family history of diabetes were questioning why they had developed diabetes. As P6 describes it: “My entire family is not diabetic (so I started wondering) why I had diabetes”. A second participant remembered the initial reaction to the diagnosis as: “I’m the first one in the family to have diabetes so there is a lot of ‘Why me?’” (P3).

With the diagnosis, issues surrounding the hereditary aspect of diabetes became a question for some participants. This included reflecting back on family members of previous generations that might not have been diagnosed. P1 was referring to this aspect: “(I) often also wonder about my grandmother”. For participants with family members with diabetes, diagnosis was not as much of a ‘shock’. They felt that this explained to an extent why they had developed diabetes. One participant explained: “My brother and sister all had diabetes” (P1) and another participant realised: “it is from my mum’s side” (P5).

A main concern for participants was the protection of future generations in their families from developing diabetes. Participants discussed the use of knowledge gained from the self-management programme to educate close family members, particularly siblings, children, grandchildren. As one participant put it: “I have warned my various hereditary line...it is just for them to be aware” (P1). A second participant added: “I’m telling lots of my family (about the information received at the programme)” (P5).

Summary

Overall, participants reported implementing a number of diabetes-related behaviours and resulting benefits in regard to their health. Participants used comparison between themselves and other people with diabetes or other illness. In general, participants felt that they were ‘better off’. Participants felt that they were better equipped to deal with the ‘food police’ since attending the programme. All participants discussed weighing up the benefits of the healthy eating guidelines and making decisions about when to

deviate from these guidelines on occasions. Participants viewed support received from family and friends in regard to their diabetes positively, with some negative aspects being discussed.

While some programme content impacted negatively in the short term on participants' quality of life, strategies were developed to turn this into a more positive experience. Participants used the interviews to reflect back on the immediate time after initial diabetes diagnosis and the resulting concerns in regard to their families. Overall, this group of participants felt that the self-management programme helped them to establish changes that resulted in an improved quality of their life. One participant summed it up:

“In a way I just want to be able to live. Diabetes, it’ll go into its position”

Chapter 9 Follow-up telephone interview

or

“Changes? Not really, but settled into a comfortable routine”

9.1. Introduction

The focus of this chapter is on participants' reports in regard to their experiences of living with diabetes over the three-month period since the first interview. No verbatim quotes of the participants can be provided in this chapter because the follow-up interviews were not tape-recorded but rather notes were taken for the duration of the phone conversation. The main themes that most participants brought up during these conversations were:

- Maintenance of diabetes-related behaviours
- Settling into a routine
- Reflection on participation in the course and the research project

Individual participants talked about increasing or decreasing established behaviours and one participant added information in regard to recruitment of future participants. These aspects will be discussed as one theme “individual participants” in the current chapter.

9.2. Maintenance of diabetes-related behaviours

All participants reported that in general they maintained the diabetes-related behaviours that they had initiated during, or shortly after the end of, the diabetes self-management course. Participants talked about feeling confident that what they were doing was working for them and that they were very happy with the way things were going for them at the current stage.

9.3. Settling into a routine

All participants mentioned at some stage during the follow-up interview that they had settled into a nice and comfortable routine, and that they were happy with the way their diabetes was going for them. The comment of one participant, which was echoed by most participants, was that the person was used to doing things (diabetes-related behaviours) properly now so there was no need to change anything. One participant commented that life was good, with another participant pointing out that even though it was a different way of life now than anticipated, it was still a good life.

They all reported that for now they would go on with their current routine but realised that under different circumstances they might have to change or adjust their current routine. Participants mentioned that they felt confident in what they were doing seeing they had seen the benefits of their current routine. These benefits included weight stabilisation or loss, HbA1c and regular blood glucose readings within the normal range and, for people on diabetes medication, no increase or even a reduction in dosage.

Participants talked about feeling relaxed about their routine these days and that they did not have to think about what they had to do anymore. The diabetes-related behaviours had become part of their daily life and routine and were no longer an issue or a hassle. Some participants felt that since the initial interview they enjoyed going out to functions or restaurants again as they now had a better understanding of how the food would impact on their blood glucose levels, and what they could do to prevent these levels from getting too high.

Most participants pointed out that over the last three months their blood glucose levels were generally in the normal range. One participant talked about blood glucose levels above the normal range although they were steadily decreasing. Participants reported an increase in confidence and less worry when it came to having too high or low blood glucose level readings, because they were aware now and able to trace it back to its cause.

9.4. Reflection on participation in the course and research project

9.4.1. Reflection on participation in the course

All participants stressed again at some stage during the follow-up interview how much they appreciated that a course like this was offered. They talked about how the course was not only a success in regard to improving their own health, but also in providing them with the confidence and knowledge to teach others. One participant added that people are lucky to have the opportunity to attend a course like this.

9.4.2. Reflection on participation in the research project

Participants surprised me with their comments about my attendance of the course and my research. They talked about how important they thought it was that I attended all

the sessions to gain an understanding what went on in each session. They mentioned that this understanding (or knowledge) helped during the interviews when they referred to situations or content, as there was no need for long explanations. Participants mentioned that they appreciated the fact that they could ask me questions during the course in regard to my research. This made them feel very comfortable about participating in the interviews, because they knew who I was and what the research was all about. During the follow-up interview participants also thanked me for calling them again after three months to find out how they were doing now. They said that this showed that I cared about them and that I was interested in their diabetes care information as well. Participants expressed appreciation at being involved in the research and also remarked on their view that the research was ‘important’.

9.5. Individual participants

This section reports on important information provided by some participants in the follow-up interview. While relevant to the evaluation, and important to some individuals, these aspects were not mentioned by the majority or all participants.

9.5.1. Increasing diabetes-related behaviours

Some participants mentioned a short-term increase of their physical activity during the summer months. The specific activities named by participants were an increase of their physical workload, uptake of swimming, and planting a vegetable garden. None of the participants planned to continue these activities after the summer.

One participant reported being more confident about changing and adapting existing recipes to suit the established healthier lifestyle. Another participant added that the adaptation of recipes resulted in positive reactions from extended family members. These reactions were used to teach family members about diabetes and healthy eating.

9.5.2. Decrease in diabetes-related behaviour

Three participants reported that they were doing less blood glucose tests each week, and this was the only decrease in diabetes-related behaviours. Participants emphasised that this decrease was based on health professionals’ recommendations after their blood glucose levels had returned to a normal level. Participants talked positively about this decrease as they felt it highlighted that their current routine was beneficial to them.

9.5.3. Adding information to an existing theme

During the phone interview participants were provided with a brief initial summary of the research findings. All participants reported that this was a good summary of their feelings after completing the course. When asked if their feelings in regard to any aspect had changed since then, six participants answered “no”. Only one participant’s feeling in regard to attending the course had changed. That participant felt that informing a support person about the course content was more difficult than initially anticipated. The participant stressed that future participants should be made more aware of the benefits of having a support person attend the programme.

Summary

Participants had generally maintained their diabetes-related behaviours at the follow-up interview. All participants reported that they felt confident about their routines. They had settled into their routines and did not anticipate making changes in the near future. Some participants mentioned short-term increases in physical activity and increases in adapting recipes. Three participants decreased their regular blood glucose testing following a health professional’s recommendation. Participants appreciated the fact that this programme was offered and felt that by contributing to this research they had made a difference for future participants.

Chapter 10 Discussion

Looking back and implications for the future

10.1. Summary of results

This is the first qualitative study to evaluate the effects of a diabetes self-management programme as experienced by the participants with Type 2 diabetes in Whangarei. The study also evaluated participants' perceptions of the programme's impact on their self-efficacy and quality of life. Interviews took place shortly after the course finished and at a 3-month follow-up. This study showed that participants viewed the programme as beneficial to them and had improved their self-efficacy and quality of life. According to participants, the benefits of attending the programme included increased knowledge in regard to self-management, incorporating new self-management behaviours, educating others, increased confidence and positive outlook in regard to their current and future life. The follow-up evaluation highlighted the benefits of settling into the previously established routines and the positive aspects of participating in the study. As this study evaluated distinctively different aspects it was not expected to find one overarching theme, but rather different themes describing each evaluation component. The main themes identified represented each evaluation component and highlighted the existence of a fourth (and unanticipated) theme.

Experiences of the course

The theme "Six weeks sounded too long, but it was worth the time", reflects participants' experiences of the course. Committing to attend a course over the period of 6 weeks played an important role in participants' decision to enrol. It was difficult to envision how the time could be filled in regard to information surrounding diabetes and diabetes-related behaviours. For the current participants these concerns proved unfounded as they experienced the time as passing very quickly.

A second key feature of this theme was the relevance of the programme content to participants' lives. Participants liked most content and suggestions were provided to change or improve content that was disliked for future participants. Participants were very positive about the course delivery mode of group teaching. This delivery mode enabled participants to provide and receive support from each other and the group

leaders. All participants felt that the programme should be offered in the future and were already recommending it to other people in the community.

Self-efficacy

The theme “I know what I need to do and I’m confident to do it” highlights participants’ perceptions of their self-efficacy after attending the course. A key feature of this theme is the new acquisition or confirmation of knowledge in regard to diabetes self-management. Participants linked this knowledge with an increase in confidence to initiate and maintain self-management behaviours. Self-efficacy can be seen as a link between knowledge and actual behaviour and participants’ perceptions reflect this definition. Participants reported an increased feeling of confidence of being in control of their present and future life and self-management. These feelings represent high expectations as participants related their beliefs in their ability to control their diabetes to all aspects of diabetes self-management behaviours.

Participants further talked about having the confidence to educate others in regard to diabetes and its management. This subtheme can be linked to self-efficacy theory’s dimension of generality (Bandura, 1997). Participants’ beliefs in regard to their ability to manage their diabetes remain in these specific albeit numerous and diverse situations. However, by educating others, participants transferred their self-efficacy expectations to other situations. In regard to the strength of self-efficacy experienced following the course, participants reported high expectations after attending the programme, and especially at the 3-month follow-up. Participants were certain that they would be able to maintain the current routine and believed that they would be able to slow down the progression of diabetes through good control.

An important and unexpected subtheme in regard to self-efficacy was the confirmation of having diabetes (for recently diagnosed people). While participants had received a medical diagnosis before attending the course, it was through the attendance that they accepted the diagnosis. Attendance at the course highlighted that the knowledge gained was relevant and applicable to their lives.

Bandura (1997) discusses different primary sources of information and learning that interact to create self-efficacy beliefs. Participants provided a number of examples of the ways in which they and the course leaders employed the different primary sources of

‘mastery enactment’, ‘vicarious experiences’, ‘verbal persuasion’, ‘physiological states’ and ‘imaginary experiences’, during the evaluation. Participants learning to do their own blood testing, preparing healthier meals, and finding their own most suitable physical activity, are all examples of mastery enactment experiences, which are seen as the most important source of learning. During the interviews participants discussed the benefits of attending a group programme, as it allowed them to learn from other people with diabetes. Bandura defined this type of learning as vicarious experiences, another primary source.

The programme leaders used verbal persuasion, another primary source, to instil in participants the belief that they can manage their diabetes. Participants made references to this source, viewing the leaders as capable and knowledgeable, which are important aspects to ensure the effectiveness of this source. Physiological states, including control of blood glucose levels, play an important role in diabetes management. Participants discussed this primary source and their resulting ability to avoid feeling unwell and prevent unhealthy high blood glucose levels. When discussing diabetes management in the future, participants utilised the last primary source of imaginary experiences, describing how they will be able to avoid long-term complications and stay active.

Overall, it appears that these participants’ self-efficacy in regard to living with and managing their diabetes increased after attending the diabetes self-management programme and was maintained at a 3-month follow-up. Participants utilised the different primary sources of information and described how they increased their confidence in regard to their diabetes and their established routine.

Quality of life

The theme “Life is good, diabetes is just another thing to handle” summarises participants’ perceptions in regard to their quality of life. The quotation used to illustrate this theme highlights the important perception that diabetes-related quality of life plays an important role but is just one aspect in regard to their quality of life. While diabetes-related quality of life has been separated into different components in the literature (perceived health status, health-related quality of life, reduced symptoms and satisfaction with the programme), participants did not specifically make these distinctions. However, most participants discussed some of these different components during the interviews, often in relation to each other.

Participants assessed their own quality of life in relation to other people with diabetes or other illnesses. Participants also used retrospective assessment of their quality of life by comparing how they were doing at the time of diagnosis compared to the present. In general, they felt that they were better off, compared to time of diagnosis and compared to others. Participants additionally discussed the negative aspects of their quality of life. These negative aspects were often framed in relation to diabetes, its impact on their present and future, and their relationships with others. Overall, participants rated their health status and health-related quality of life as very good, particularly after they incorporated some behavioural changes into their routine. Participants were very satisfied with the programme and its impact on their life.

Maintaining routine

The follow-up interviews highlighted a fourth theme important to participants: “Changes? Not really, but settled into a comfortable routine”. Participants had discussed numerous changes to their daily routine at the initial interview. At the second interview they felt that they had developed a routine that worked well for them in regard to controlling their diabetes and their life. Three months later, importance was placed on maintaining diabetes-related behaviours and making small adjustments to the routine if and when necessary. Decreases in diabetes-related behaviours had only occurred after these were recommended by a health professional. Participants used this time to reflect positively on their participation in the course and this study.

10.2. Results and relevant literature

The overall results in regard to participants’ experiences of the programme and their perceptions of their self-efficacy and their quality of life at the initial interview were very positive. Participants reported settling into a good routine at the 3-month follow-up interview. They also reported important physical changes including reduction in weight, blood glucose testing (as levels are at or close to normal levels), and reduction in medications. It is important to consider how these results fit into the existing self-management programme research.

Participants’ positive experiences of attending a supportive group education programme are in accord with findings from similar programmes (Barlow et al., 2005; Monninkhof et al., 2004; Dongbo et al., 2006). It highlighted that content of the programme was

generally well liked and that the support (from group leaders and other people with diabetes) helped them in making changes to their diabetes-related behaviours. This qualitative study also identified participants' decision-making processes when it came to enrolling in the programme.

The diabetes self-management programme was designed to improve self-efficacy and this study showed that participants believed the course provided them with the confidence to initiate and maintain diabetes-related behaviours. It is important to note that this confidence was linked with new and confirmed knowledge received at the course. Monninkhof et al (2004) point out that acquired knowledge leads to effective management, which in turn leads to greater self-efficacy and a more positive outlook for the future.

This study also highlighted that, for a small group of people with diabetes, attending such a programme helped to confirm the diabetes diagnosis. Studies in regard to patients' reactions to diagnosis have indicated the preference for a second diagnosis. In a Scottish sample, following the diabetes diagnosis from a GP, many people still preferred to receive a second diagnosis from a medical professional at the hospital (Parry, Peel, Douglas & Lawton, 2004). Particularly for asymptomatic individuals receiving a diagnosis of diabetes can be problematic. Peel et al. (2004) discuss in their findings the importance of receiving 'proof' of having Type 2 diabetes. Diagnosis might be seen as objective 'proof' but as it appears this is not the case for all people. It appears that in the current study, participants believed that they received this 'proof'. It was not received in form of a second diagnosis but rather through relevant information in regard to diabetes-related behaviours and symptoms. This information was received from the group leaders and other participants attending the course.

Participants assessed their current quality of life by comparing their lives now and at diagnosis. Participants reflected back on receiving the diagnosis, either as something expected (having suspected diabetes) or unexpected (routine check-up). Peel et al. (2004) describe the three different pathways to diabetes diagnosis as 'suspected diabetes route', 'illness route' and 'routine route'. Reactions to diagnosis depended on the route through which diagnosis occurred. 'Shock' was described by some participants, as was

the case for most participants in the current sample. Most participants discussed that these feelings were short-lived and that their life was much better now.

Participants were using social comparison to assess their quality of life. Participants compared themselves to other people with diabetes, both from the group and other settings. Participants also compared themselves to others with different conditions. Buunk, Gibbons and Visser (2002) discuss the notion of upward and downward comparisons. Evidence suggests that both types of comparisons can be beneficial for people with chronic illnesses. Making downward comparisons are generally used to evaluate ones' own situation, while upward comparisons are used for seeking information (Bennenbroek, Buunka, van der Zeeb & Grol, 2002). Downward comparisons are often cognitive processes while upward comparisons happen through affiliation.

In the current study, participants used downward comparison to evaluate their own situations, leading to the conclusion that they are better off. In general, these comparisons were made in relation to people they knew in their private life, rather than other course participants. Participants discussed some aspects of upward comparisons relating these to the group context. Participants' comments relating to upwards comparisons included the benefits of having people on the course whose time of diagnosis differed from their own. This provided for newly diagnosed participants a 'benchmark' of where they could be heading with their diabetes, while for participants diagnosed at an earlier stage it provided a reminder of how far they have come already. Participants talked about the benefits of all participants having Type 2 diabetes, therefore allowing for a more specific comparison. An important aspect for some participants was the fact that nobody was using insulin. These comments could be viewed as either upward or downward comparison, as participants benefited from seeing others that were controlling well without the need for injecting insulin (upward comparison). At the same time they did not have to meet somebody who had started injecting insulin, a path that they are still trying to avoid or delay (downward comparison).

As Williams and Bond (2002) discuss, social support plays a role in self-care and the findings of this study support this suggestion. In particular, this qualitative study

highlighted that social support for participants had both positive and negative aspects. Family members could both be helpful in regard to diabetes-related behaviours, yet at the same time overbearing or uninterested. Hendy and McVittie (2004) discuss these ambivalent views in regard to older peoples' life experiences and the difficulty in measuring these quantitatively.

10.3. Limitations of the study

Participants were satisfied with the programme and viewed attending it as beneficial to them. Participants' perceptions of their self-efficacy and quality of life were very high. These are very positive results and there are a number of possible explanations, which will be considered in more detail.

One possible explanation for these results is that this study focused exclusively on participants' subjective experiences and perceptions. For the purpose of this study no objective data was specifically collected. However, during the course of the interviews participants discussed some indicators of objective information that mirrored their subjective perceptions. This information included weight loss, reduction in blood glucose levels and medication.

A second explanation comes from the group of participants themselves. Participants were very motivated about attending the programme, rarely missing a session. Overall dropout rate was very low; only 4 people left after one or two sessions and did not complete the programme. Of these, 3 people asked to be put back on the waiting list to attend a later course that would be more suitable for their current life. As participants pointed out, the length of the course, although initially impacting on their decision to attend, did not finally deter them from enrolling. This group of participants committed themselves to attend and might therefore have been highly motivated to change and receive the greatest benefits from attending the programme. All the interviewed participants were very confident about their self-management routine, whether they attended all sessions or missed some. This could be another indicator that they were highly motivated to change before attending the programme. Participants were very clear why they did not attend specific sessions, having often previously attended a similar session.

Of the group of participants that attended all or most sessions, a small number chose not to be interviewed. One participant attended only the first two sessions before leaving the programme. Reasons for this are unknown and the person chose not to be interviewed. It is possible that these participants might not have the same positive feelings about the programme compared to the interviewed participants. Furthermore they might not have derived the same benefits from attending the programme. Potentially the programme might not have impacted as highly on their self-efficacy, quality of life or self-management behaviours.

Participants mentioned different health professionals who recommended the programme to them. There are only a certain number of spaces available per year and health professionals might not recommend the programme to all their clients. The programme might only be recommended to people with diabetes they view as the most likely to change and maintain diabetes-related behaviours. Even if health professionals recommend the programme to all their clients, only the people most committed to change might decide to enrol. Finally, as there are individual education options available to people with diabetes, some might prefer these to a group-education programme as well. Some participants raised the question as to why there weren't more Māori participants considering Northland's population mix. Participants discussed a number of potential ideas. Investigating these ideas is beyond the scope of this study. Māori were underrepresented in the current sample but it is unclear if the same is true for the participation in the programme in general. Long-term ethnicity data collection would highlight if Māori continue to be underrepresented as participants. This could be a potential concern as Māori are statistically more likely to develop serious long-term complications. Research into referral rates, enrolment and education choices might provide further information towards representation of Māori in this and other self-management education options.

Another aspect that needs to be considered is the impact of the researcher in regard to participants' outcomes. A relationship had developed during the course attendance and participants were informed about the 3-month follow-up. Participants mentioned that they appreciated the follow-up interviews. Participants thought that it showed that not only did I care how well they were doing shortly after the course, but later on as well.

The knowledge that the follow-up interview would take place could have encouraged participants, to some extent, to maintain their self-management behaviours over time.

Finally, the follow-up interview took place 3 months after the initial interview. It is possible that participants' positive feelings about the programme might have resulted in short-term changes. These reported improvements and established self-management routine in the short-term might not be maintained over time.

10.4. Implications for the future

This study has implications for self-management programmes in general and the diabetes self-management programme in Whangarei. Some insights could be gained from participants' experiences and perceptions about the programme and its effectiveness. Some questions were raised surrounding referral to the programme, who attends and benefits from the programme, the programme's effectiveness in the long-term and the impact of follow-ups on self-management behaviours.

Participants mentioned different health professionals who had recommended the programme to them. These recommendations raise some questions that are beyond the scope of the current study but it would be worth researching in the future. As participants received recommendations from different health professionals, it would be worth looking into whose recommendations participants are most likely to follow. Are there certain health professionals in the community who recognise the value of the programme more than others? Some people who might benefit from attending such a programme could miss out, as they are not informed of its existence. Results from the current study could potentially be collated to provide a short overview of participants' experiences and perceptions that might be of interest to health professionals and potential future participants.

Another aspect that should be the focus of future research are the people with Type 2 diabetes themselves. Once it has been established how many people have received a recommendation to attend a course it would be important to see who takes up the recommendation and enrolls. It is possible that this is a subgroup of people with Type 2 diabetes who are already highly committed and motivated to change. An interesting aspect that research might highlight is when participants decide to enrol. Some might

prefer to enrol once they have been newly diagnosed, while others might prefer to enrol at a later stage. This information should be collected long-term to provide some insight.

People with Type 2 diabetes who receive a recommendation to attend the programme have two further choices; to attend no education programme at all or to receive individual education. To look at the effectiveness of the diabetes self-management programme, future research should track how well people with Type 2 diabetes are doing in regard to these options. Comparing people depending on their choice of education could establish effectiveness of each choice and highlight reasons for choosing a specific option.

Participants' experiences of the programme support the use of this programme as a means of providing self-management training for people with Type 2-diabetes. Participants discussed some suggestions, which could be used to modify specific content of the programme. Most participants expressed the wish for a follow-up session to meet up with group leaders and other participants. This follow-up could be used to provide the latest information in regard to diabetes management. It would be worth researching whether this follow-up session has any impact on the effectiveness of participants' self-management, self-efficacy and quality of life.

The current study focused on participants' self-reported perceptions in regard to self-efficacy and quality of life. Participants' expressed a high degree of self-efficacy and positive quality of life. As interviews took place shortly after attending a course and 3-months later, long-term effectiveness of the programme could not be established. Future research could provide insight into the long-term impact of the programme on participants' maintenance of diabetes-related behaviours, self-efficacy and quality of life. Future data collection could include more objective measures as an added information level. Information collected could include blood glucose level measurements, weight and medication (decrease/increase and time period). This information could easily be added to the short demographic questionnaire already given to participants or collected from health care professionals.

The current study focused on the experiences and perceptions of people with Type 2 diabetes. Support people who attend the sessions were excluded from the current study.

Future research might look into support people and their experiences of the programme. The impact of attending a course and its impact on support peoples' self-efficacy and quality of life should also be considered. Does the information provided help them when it comes to living with the person with Type 2 diabetes? Or is the information decreasing their quality of life as it increases their worry and concern? One participant of the current study came to realise after the course ended that it would have been beneficial to have a support person attend at the same time. The feeling was that this would have been easier compared to trying to educate the person after the course ended. This comment raises a number of questions that could be studied further. As not all course participants have a support person with them, is there a difference in the course experience, self-efficacy and quality of life between people with a support person and without?

Participants' comments in the follow-up interview of the study were the most surprising finding of this study. Even though participants had been informed about the follow-up interview, they appreciated this call as a sign of care and interest in their health. It is unclear if anticipating this call had any positive impact on participants' self-management behaviours. Future research might provide insights into this. However, looking at participants' reactions to the call, programme providers might consider incorporating these short follow-up calls into their programme design. If people are informed of these follow-up calls while attending a course, this knowledge might impact positively on the maintenance of their self-management behaviours. As it is often the case with programmes, once participants leave they are expected to look after themselves as they have been given all the information necessary. Providing this follow-up call might give participants further motivation to integrate self-management behaviours into their routine. The knowledge that group leaders are still interested in them and their health might have additional benefits to participants' quality of life.

A further benefit of this follow-up call is the fact that it reaches all people that attended a course and not just participants that chose to participate in research. Participants that decide to be interviewed for the study might be a subgroup that is doing particularly well. Follow-up calls as part of the programme would highlight how everybody is doing, thereby providing a more detailed picture of who benefits most from attending self-management programmes in the short- and long-term.

10.5. Conclusion

This study is the first evaluation of the diabetes self-management programme in Whangarei. It highlighted that participants view attending a course as being beneficial to them. Participants liked the content of most sessions and are recommending the programme to others. Participants benefited from the group-teaching component, receiving information and support from the group leaders and other participants. Participants reported improvements in regard to self-efficacy and quality of life at the initial interview. Behavioural changes, social support and social comparisons played an important role in participants' assessment of their quality of life. These reported improvements were maintained over a 3-month period at which time participants had settled into a comfortable routine. The programme provided participants with the knowledge to confidently initiate and maintain their diabetes-related behaviours. Participants positively discussed their participation in the current study and appreciated the follow-up interview as a sign of 'care'.

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Appendix A



Massey University
COLLEGE OF HUMANITIES AND SOCIAL SCIENCES

SCHOOL OF PSYCHOLOGY
Te Kura Hinengaro Tangata
Private Bag 11 222
Palmerston North
New Zealand
T 64 6 356 9099 extn 2040
F 64 6 350 5673
www.massey.ac.nz
<http://psychology.massey.ac.nz>

Qualitative evaluation of a Type 2 diabetes self-management course in Whangarei

Participant information sheet

My name is Daniela Andrae and I am working towards a Master of Arts in Health Psychology with Massey University, Palmerston North. As part of this degree I am currently undertaking a research study for my thesis. My interest in the area of diabetes arose through a practicum at the Diabetes Lifestyle Centre and the observation of the first self-management course offered by Manaia Health PHO. My specific interest in this study is how people with diabetes experience these courses and how attending the course will affect the person.

My supervisor for this study is Dr. Christine Stephens, a senior lecturer in the Department of Psychology, Massey University.

Contact details:

If you have any questions or require further information regarding the study you can write, phone or email:

Contact details: Principal investigator
Manaia PHO
Attention Daniela Andrae (researcher)
P.O. Box 1878
WHANGAREI

Phone: 0800 blank (through Massey University)
Email: d.andrae@hotmail.com

Contact details: Supervisor
School of Psychology
Massey University
Private Bag 11 222
PALMERSTON NORTH

Phone: (06) 350 5799 ext 2081
Email: C.V.Stephens@massey.ac.nz

Your involvement:

As a person with Type 2 diabetes, who has recently attended the diabetes self-management course offered by Manaia Health PHO, I would like to invite you to participate in this study.

Education about diabetes self-management is an important aspect in diabetes care but it is as important to look at how well and what kind of differences the courses make to the

participants. I am interested to learn about your experiences of the course, if the course was useful to you, what you liked or disliked and what have taken away from the course. I am also interested in whether the course impacted on how you are managing your diabetes and its impact on your daily life.

At this stage, no research study has explored participants' experiences and opinions of the benefits of the course. I hope that this study will provide some information, which would help to improve the courses and give future participants and health professionals your opinion about the course.

The study

Your input will require one, possibly two interviews and filling out a brief background questionnaire (at the first interview). The information from the questionnaire will be used for statistical analysis only.

The first interview will take approximately 1 hour. During this interview, you will be asked to discuss your experiences of the course and its impact on your diabetes management and daily life. The interview will be held at your home or an office at Manaia Health PHO, depending on your choice. As a thank-you for your time spent during this interview you will receive a \$20.00 supermarket voucher.

The second interview, 3-months later, will be a shorter (15-20 minutes) phone interview. This will be used to verify with you my interpretation of the first interview. I will also be interested to hear how you are feeling now and if anything has changed regarding your diabetes management.

All interviews will take place between September 2007 and March 2008. The interviews will be informal, as if we were having a conversation. A tape recorder will be used to record the first interview with your permission. This will help me refer to it after the interview, when I transcribe the data from the audiotape into written form. I can provide you with a short verbal report of the first interview outcomes at the 3-month follow-up interview. You can receive a written report of the overall results by all participants once the study is completed.

All information (interview content and questionnaire) received from you during this study will be kept completely confidential. Your name or other identifiable material will not be available to anyone other than the investigator and her supervisor, will be stored in a secure place and will not be used in any reports on this study.

A thesis will be prepared from the provided information, and reports to the PHO and other health care providers, journal articles, and possibly conference material based on this study may follow this.

I would like you to consider taking part in this study understanding that your involvement is entirely voluntarily. If you do agree to take part you are free to withdraw from the study at any time without having to give a reason and this will in no way affect your future health care.

You have the right to

- receive this information sheet and decline to take part in this study
- withdraw from the study at any time

You also have the right at any time during your participation to

- ask any questions about the research
- choose the place the first interview is being held
- refuse to answer any question
- request that the recorder is switched off
- stop the interviews at any time
- be verbally informed of the interpretation of your results
- receive a written summary of the findings once the project is completed
- provide information on the understanding that your name or any other identifying details will not be used and that no one other than the researcher and the supervisor will have access to the information
- provide information on the understanding that the information (questionnaires, transcripts, tapes) will be stored securely and destroyed after 5 years
- know that the study will have no connection at all with your continued involvement and care at Manaia Health PHO

Concerns

If you have any queries or concerns regarding your rights as a participant in this research study, you can contact an independent Health and Disability Advocate. This is a free service provided under the Health & Disability Commissioner Act:

Telephone (NZ wide): 0800 555 050
 Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)
 Email: advocacy@hdc.org.nz

Ethical approval

This study has received ethical approval from the Northern X Regional Ethics Committee. The clinical board at Manaia Health PHO has given permission for this study to be carried out.

If you are willing to participate in this study, please complete the enclosed consent form concerning the use of the information and return post this form to me using the supplied envelope.

Thank you

Daniela Andrae
 (Principal Investigator)

Phone: 0800 (through Massey University)
 Email: d.andrae@hotmail.com

Appendix B



Massey University
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http://psychology.massey.ac.nz

Consent to participate in study

Qualitative evaluation of a Type 2 diabetes self-management course in Whangarei

This is to confirm that I have read and understood the information sheet dated 23/08/2007 and had the details of the study explained to me. I have had the opportunity to ask questions about the study and had them answered to my satisfaction. I have had the opportunity to ask my whanau to help with these questions.

I understand that taking part in this study is voluntary (my choice) and I am aware that I can withdraw from the study at any time and decline to answer any questions I do not wish to answer.

I agree to provide information to the researcher on the understanding that my name and any other material, which could identify me, will not be used in any reports regarding the study.

I consent to my initial interview being audio-taped Yes No
I have been advised that I have the right to ask the recorder be switched off at any time during the interview.

I agree to participate in the 3-month follow-up telephone interview Yes No

I would like the researcher to discuss and verify the outcomes of the initial interviews with me at the 3-month follow-up telephone interview Yes No

I would like to receive a summary of the overall results, once the results have been published Yes No

I agree to take part in this study under the conditions set out in the information sheet and know who to contact with any future questions or concerns.

Signature: _____ Date: _____

Full name-printed: _____

Contact phone number: _____

Contact address: _____

*Please return this form in the enclosed envelope which is addressed to:
Manaia Health PHO, Attention Daniela Andrae (the researcher), PO 1878, Whangarei.
Please note that you do not need to use a stamp on this envelope. Postage is paid.*

Version no.2: 23/08/2007



Appendix C

Demographic information

1. Gender: Female Male

2. Age at last birthday: _____

3. Which ethnic group do you belong to? (Please tick the space or spaces that apply to you)

New Zealand European

New Zealand Maori

Samoan

Cook Island Maori

Tongan

Niuean

Chinese

Indian

Other (such as Dutch, Japanese). Please state: _____

4. Are you currently (please tick one)?

married or domestic partner

divorced

single

widowed

separated

Appendix D

Researchers reference guide of questions for participants

Initial Interview guide

A) Evaluate participants' experiences of the diabetes self-management course

Do you feel the course was worth your time?

What did you get out of the course?

What are the main things that you learned, things that you remembered most?

What part or parts of the course did you like the best/ the least?

B) Explore participants' perceptions of how the course improved their self-efficacy in regard to diabetes-related behaviours

Part of the course was information in regard to....

a) diet b) physical activity c) medications/blood tests

Are you more aware of

a) healthy eating habits

b) the role that physical activity plays in managing your diabetes?

c) diabetes medication management strategies and what your blood results mean?

Do you feel more confident in regard to a), b) or c) after attending the course?

Please explain

In what ways do you feel has the course helped you to improve your everyday self-management of diabetes? (Please explain)

How confident are you to continue these new self-management behaviours?

C) Explore participants' perceptions of their quality of life after attending the course

Have you changed any of your diabetes-related behaviours after taking the course?

Has the course changed your future outlook on your life? (Please explain)

Are there any aspects of your life that you feel more positive about since taking the course? (Please explain)

Do you feel the course had any negative effect on your life? (Please explain)

Is there anything you would like to add about your experiences that we haven't covered yet?

Appendix E

Researchers reference guide for the follow-up interview

Interview schedule at 3-months follow-up (telephone)

Short overview of results for participants

Is this a good summary of your feelings when you completed the course? Yes/No

Have your feelings changed since then?

Have you been able to maintain your diabetes-related behaviours discussed during the first interview? (Please explain)

Have you been able to initiate new behaviours over the last three months? (Please explain)

Is there anything else that you would like to add?