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**“It’s a whole package”: Type 2 diabetes and what it
means for the body, life and self of people of Indian
origin in New Zealand**

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Abstract

Type 2 diabetes represents a considerable health problem for the Indian population group in New Zealand. In order to minimise the risk posed by this disease, recommended therapeutic goals include glycaemic control, maintaining a healthy weight and strict control of blood pressure. Culturally derived understandings of the illness and options for management will affect the way in which the person of Indian origin reacts to diabetes. This study looked at the way in which Type 2 diabetes is constructed and positioned while reflecting on how Indian culture might affect the way in which diabetes is interpreted and experienced. Seven males and five females, identifying themselves as being of Indian origin and managing Type 2 diabetes without the use of insulin were selected for the study. Semi-structured interviews were taped, transcribed and analysed using a reflexive approach to Foucauldian discourse analysis

Understanding diabetes begins through describing and accounting for the diabetic body which is believed to be different to other bodies. The way in which the person with diabetes might chose to control the disease and minimise harm to the body is validated by particular beliefs in cause and nature. As a result, the person with diabetes is able to construct a constantly evolving picture of the way in which the disease develops, what can be expected of it and what diabetes means for them, for their families and social connections. All this takes place within the particular social and cultural perceptual system of the person of Indian origin and the environment within which they live their every-day lives. The person with diabetes is actively engaged in processing new information, weighing options and defining who they are, not merely as someone with diabetes but as multi-dimensional individuals. Drawing on different constructions of the self, to justify and explain actions taken, opens up or limits access to opportunities to make changes and embrace new behaviors to manage their diabetes.

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The face of disease in society has changed. In the past, disease was defined largely through infectious diseases and epidemics. The waning of the epidemic in modern times, particularly in industrialised countries, is largely due to improvements in sanitation, nutrition, housing, access to health care and drinking water. With the waning in prominence of epidemic diseases, our understandings of how we become ill have also transformed in order to account for the comparative rise in other diseases and corresponding changes in the way in which we deal with them (Radley, 1994). The rise of chronic illnesses in particular has led to a need to re-examine approaches to dealing with illness and the role and position of the patient (Bury, 1982; Anderson, Funnell, Carlson, Saleh-Statim, Craddock & Skinner, 2000). The chronic nature of illnesses such as arthritis, asthma and diabetes, and a consequent need for the ongoing management of these conditions, has challenged the status of the medical system as the source of a cure for disease (Thorne, Ternulf Nyhlin & Paterson, 2000). The status of the medical professional has also been challenged, as the successful management of a chronic disease is dependent largely on the ability of the individual to adapt available resources to their own unique situation (Thorne et al., 2000). The key concept in living with chronic illness is the idea of *living* with chronic illness, where the emphasis is not on preparing for death or in working towards a cure, but rather on continuing with life.

Adjusting to life with chronic illness involves the adaptation of existing behaviors in order to adjust to the strictures of the illness, as well as the adoption of new health behaviors relating to its management (Michie, Miles & Weinman, 2003). This is not a straightforward undertaking. The course of a chronic illness can be characterised by uncertainty rather than constancy; symptoms might improve or intensify and the course of the disease is uncertain with variation from individual to individual (Bury, 1982; Wellard, 1998). Furthermore, knowledge of what is required to manage a chronic disease does not automatically translate into the adoption and implementation of management behaviors (Bissell, May & Noyce, 2004). Managing a chronic illness

requires the formulation of a strategy concerning the best possible use of available resources; a process that is influenced by constraints placed on the person by their particular social, economic and political environments (Anderson, Dyck & Lynam, 1997). With the prospect of long-term health-related issues, there are several concerns, such as the cost of medication and dietary requirements, the impact of ill-health on the ability to work, time considerations and the requirements of other family members that play a part in the re-organisation of life around a chronic disease (Anderson et al., 1997; Bissell et al., 2004). We are therefore faced with the challenge of caring for the chronic sufferer and supporting the effective management of these conditions, which necessitates first understanding the issues involved.

Our understandings of particular chronic illnesses have similarly changed through the centuries. In 1550BC, the first known reference was made in Egyptian texts to a disease with symptoms that are now attributed to diabetes (Diabetes Forum, n.d.; University of Michigan Health System, n.d.). Indian texts of the same era describe the disease and attribute it to the overindulgence of food and drink (Diabetes Forum, n.d.). Through the centuries, understandings of the nature of the disease varied, as did the recommendations to deal with it; one school of thought advocated the replenishment of sugar lost in the urine, while another believed the problem stemmed from excess sugar and therefore recommended limiting its intake (Diabetes Forum, n.d.). The 19th century saw several developments, such as the discovery of specialised cells within the pancreas and their role in diabetes, and this led to our current understandings of the disease (Diabetes Forum, n.d.; University of Michigan Health System, n.d.). In 1997, the American Diabetes Association (ADA), endorsed by WHO, classified diabetes into four main types; Type 1 diabetes, Type 2 diabetes, other specific types and gestational diabetes (Krentz & Bailey, 2005). Type 2 diabetes, also known as non-insulin dependent diabetes mellitus, is now understood to be a chronic metabolic disorder that develops due to the resistance of body tissues to insulin action and/or an insulin secretion defect due to defective β -cell functioning leading to pathological blood glucose levels (New Zealand Guidelines Group, 2003; Krentz & Bailey, 2005).

The term ‘diabetes’ is derived from a Greek word meaning *siphon* or *the passing through of water* and ‘mellitus’ is from a Latin word meaning *honey-sweet* (Diabetes

Forum, n.d.). The name reflects our earliest understandings of the disease as characterised by the secretion of urine with a high sugar content (Diabetes Forum, n.d.). Currently, there are several clinical features recognised as symptoms of the disease, including polyuria, nocturia, fatigue and recurrent infections, though presenting features can differ from individual to individual, ranging from a few symptoms to a life-threatening hyperosmolar, non-ketotic coma (Krentz & Bailey, 2005). Patients often go undiagnosed because of the absence of any visible disability attributable to the disease and because sufferers commonly remain asymptomatic for several years (New Zealand Guidelines Group, 2003; Krentz & Bailey, 2005). There are several risk factors connected to the development of Type 2 diabetes. These include: a first-degree blood relative with a diagnosis of Type 2 diabetes, central obesity, a previous diagnosis of gestational diabetes, certain conditions such as Down’s Syndrome and some medical treatments, such as those that include β -blockers and thiazide diuretics, are also implicated in the development of Type 2 diabetes (Krentz & Bailey, 2005). This form of diabetes typically manifests in adults, though incidence is on the rise in adolescents and children (New Zealand Guidelines Group, 2003).

Type 2 diabetes is more prevalent amongst people of lower socio-economic status (New Zealand Guidelines Group, 2003). Steptoe (1998) and Morewitz (2006) assert that one possible way to account for this is that the economic hardship faced by this group translates into limited dietary options, limited education, chronic stressors and high work demands. Rates for Type 2 diabetes also differ according to ethnicity, with the highest rates in New Zealand seen amongst people of Maori, Pacific Island and Asian descent (New Zealand Guidelines Group, 2003). Differences between ethnicities could be a result of variations in physiological pathways leading to a predisposition towards certain diseases (Steptoe, 1998). For example, Prasad and Srivastava (2002) contend that being of Indian descent is associated with high levels of insulin in the blood that could lead to pancreatic problems. They also state that for a given level of obesity, the Indian race is also at higher risk for diabetes than their European counterparts because of a tendency to carry this fat as central adiposity. Morewitz (2006) argues that disparities between different ethnic groups could be explained by differences in susceptibility or that risk factors have a greater impact on one group than on another.

Ethnicity, through its associated cultural resources and cultural practices, is also relevant in issues relating to lifestyle, and consequently relevant to both the risk of developing diabetes and the management of it. For example, Tresslor and Chamberlain (2005) explain that, for the Indian in New Zealand, there are issues around the maintenance and re-negotiation of cultural practice that impact on choices surrounding diet and, due to systemic constraints related to their position as migrants, a shift towards a possibly unhealthy diet is sometimes unavoidable. So, in addition to physiological bases for the development and progression of diabetes, several psychosocial factors are implicated in an increased risk for the development of Type 2 diabetes, as well as its management and progression.

Type 2 diabetes is having an increasing effect on disability, premature mortality and the consumption of health care resources (Ministry of Health, 2003a). It forms a significant share of the burden of disease in New Zealand and incidence is on the rise. It is estimated that the number of people with a diagnosis of Type 2 diabetes in New Zealand in 2011 will be 145,000; this implies a 78% increase from 1996 which can only partly be accounted for by an increase in population (Ministry of Health, 2002). Within the Indian sub-population, the incidence of diabetes is over three times higher than for the total population (Ministry of Health, 2006). These figures are based on the prevalence of diagnosed diabetes only and do not include assumptions regarding the incidence of undiagnosed diabetes or of prediabetic states such as impaired glucose tolerance and impaired fasting glucose (Ministry of Health, 2002; Ministry of Health, 2006). While representing a considerable share of the burden of disease for New Zealand in general and for people of Indian origin in particular, Type 2 diabetes is also a risk factor for other diseases (Ministry of Health, 2003a). This includes an increased risk for macrovascular complications such cardiovascular and cerebrovascular events; microvascular complications such as glaucoma, cataract and foot disease; and other conditions associated with diabetes such as recurrent infections and fatigue (Krentz & Bailey, 2005). For the Indian ethnic group, there is a significantly higher rate of morbidity and mortality from cardiovascular disease and stroke than for the total population and this could possibly be related to the high incidence of diabetes (Ministry of Health, 2006). Therefore, in addition to a need to reduce the incidence of diabetes in

the Indian community, it is also important to simultaneously aim at minimising the impact it has.

Therapeutic goals for Type 2 diabetes include glycaemic control, maintaining a healthy weight and strict control of blood pressure (Krentz & Bailey, 2005). Maintaining glycaemic control is necessary to reduce the risk of complications and can, in many cases, be managed through supporting rigorous control over diet and exercise and the use of some medication (New Zealand Guidelines Group, 2003). Currently, glycaemic control is most accurately measured through testing for levels of glycosylated haemoglobin (HbA1c) in a blood sample (New Zealand Guidelines Group, 2003). This is a laboratory value representing average blood glucose that provides a glycaemic history for the preceding 120 days and it is recommended that HbA1c levels be as close to physiological normal as possible (New Zealand Guidelines Group, 2003). Guidelines for practitioners and consumers in New Zealand, developed by the New Zealand Guidelines Group (2003), advocate a stepwise approach to glycaemic control where insulin therapy would only be initiated if lifestyle and oral therapy regimens were to fail to maintain HbA1c at target levels. While maintaining micro- and macrovascular health and glycaemic control in diabetes could be accomplished through pharmacological interventions, failure to also include diet, exercise and other lifestyle changes, such as smoking cessation, in a self-management programme may result in higher levels of medication being used, and a corresponding increase in the likelihood of drug-related side-effects and adverse reactions (New Zealand Guidelines Group, 2003). Therefore issues surrounding lifestyle change become extremely significant, not only with regard to management of the disease itself and limiting its consequences, but also with regard to limiting detrimental effects of medical interventions.

Assistance for Type 2 diabetes in New Zealand is primarily delivered through the GP with or without the primary care diabetes nurse who co-ordinates treatment, testing and referral to services such as dietitians and podiatrists; major complications are handled through specialised care in hospitals and other settings while special interest groups provide resources for learning about the illness (Ministry of Health, 2003a). A free annual check by the GP or diabetes nurse is funded for people who meet the diagnostic criteria for diabetes, which is intended not only to provide care but also to

improve the co-ordination of the delivery of multi-disciplinary services and provide data that can be used to develop services and delivery options with a view to improving outcomes (Ministry of Health, 2003a). According to the Ministry of Health (2003a), the lack of culturally appropriate services and factors related to illness perceptions and beliefs are key barriers to improving the uptake of interventions that incorporate lifestyle change. In order to address this issue, they recommend that diabetes services be provided in settings that are not only accessible and affordable, but culturally competent as well. To be effective in motivating lifestyle change, however, it is necessary to first understand patient’s beliefs and notions regarding their illness (i.e., its cause, progression and management) and regarding the role and status of the health care professional (i.e., source of information, expert, resource, etc.).

Understandings and notions of illness and its consequences differ from culture to culture. These perceptual frameworks involve a shared understanding of resources available with which to make sense of the world, solve problems, live life and thereby construct the self in the context of these physical and symbolic situations (Benson, 2001). For example, in their study with men with diabetes of different ethnicities living in Sweden, Hjelm, Bard, Nyberg & Apelqvist (2005) saw differences in the way ‘health’ and ‘illness’ were portrayed. For Swedish men in the study the causes of diabetes were largely believed to be individual, such as obesity and the diet, whereas for Arabic participants it was a question of social relationships and the will of God (Hjelm et al, 2005). These understandings and notions are rooted in ancient cultural systems and form a contextual framework within which decisions are made regarding appropriate responses to illness. In their study on Chinese Americans with Type 2 diabetes, Chun and Chesla (2004) describe how beliefs held by their Chinese American participants regarding internal states of the body and the causes, symptoms and management of diabetes are rooted in traditional Chinese medicine. They report that participants with firm beliefs in a behavioral link to the development of diabetes, coupled with certain culturally rooted ideas of the definition of a healthy body, felt that pharmacological interventions were contraindicated as a treatment option. These cultural beliefs do not however preclude the use of biomedicine but exist alongside it. Chinese participants in a study that Hwu, Coates & Boore (2001) conducted in Taiwan reported a mixture of

health behaviors that included the use of western medicines and medical devices. Han (2000) also reports that beliefs rooted in the Korean culture and the use of traditional Korean herbal medicine still flourish within the Korean community in Australia even while participants professed satisfaction with and increased use of western biomedicine.

Within Indian culture too there are several different, ancient traditions of health and medicine such as the Ayurvedic, Unani or tribal systems that, despite localised or religious origins, have now been assimilated into modern health-related practice (Mrinal, Mrinal & Mukherji, 1995). Rao (2006) found that beliefs about health, illness and treatment options in Indian migrants in America were influenced by Ayurvedic principles, although her participants did not appear to be aware of the connection. She argues this implies that these principles are now an accepted part of “Indian belief systems” (p.156). Besides ideas about disease, how it is caused and how it progresses, these ancient systems incorporate prescriptions on how diet, exercise, prayer, meditation, etc. should be used to remain healthy or treat disease (Mrinal, Mrinal & Mukherji, 1995). This was highlighted in the study by Tresslor and Chamberlain (2005) that explored talk around food with Indian migrants. They showed how these traditional beliefs are drawn on in constructions of food and its relationship to health. Not only is it believed that an appropriate diet is a source of good health, but that food is an effective treatment for disease, and participants described ways in which food consumption changes depending on perceived threats to health (Tresslor & Chamberlain, 2005).

However, culture cannot be visualised as a stable and fixed entity but rather as a constantly re-negotiated and fluid system that is influenced, not only by history, but also by everyday existence and therefore, to some extent, by location (Bottomley, 1997). So, although Tresslor & Chamberlain (2005) report that, within the context of migration, food is a means by which cultural identity and links with the past (both individual and historical) are maintained, they also report that some dietary changes are forced due to the new demands and opportunities faced by the migrant. Similarly, in their study on Bangladeshis with diabetes in Britain, Chowdhury, Helman and Greenhalgh (2000) report that the dietary practices of their participants reflect the continuation of traditional patterns of food preparation and consumption that are modified to some extent, depending on the availability of preferred choices in their new post-migration location

and financial considerations (Chowdhury et al. 2000). So, although changes in traditional practices can and do occur, the limitations imposed by religious and ethnic prescriptions still persist. Any prescribed change in diet would therefore have to take into account existing ideas about the connection between food and health, as well as which foods are considered to be culturally acceptable and which are not.

The accepted view is that the best possible way to effectively manage Type 2 diabetes is by instituting lifestyle changes such as dietary change and increased exercise (New Zealand Guidelines Group, 2003). As discussed earlier, cultural notions and issues arising out of migration play an important part in what dietary changes are possible. An increased level of exercise also presents some cultural dilemmas. For example, cultural taboos regarding the exposure of the body, particularly the female body, and the lack of culturally sensitive facilities were some reasons why participants of Indian and Pakistani origin in the study by Lawton, Ahmad, Hanna, Douglas and Hallowell (2006) felt unable to comply with recommendations made to increase physical activity. Cultural constraints are not the only issues to be considered when proposing changes in lifestyle. Lawton et al. (2006) reiterate that a climate which is colder than that of the Indian-subcontinent and an aversion to being outdoors, particularly in winter, limits opportunities for a sustainable increase in physical activity. With regards to food, the Indian participants of Tresslor & Chamberlain (2005) also portray the use of food as being influenced by its experiential aspects, such as the pleasure and opportunities for social connection that it affords. Representations of food and exercise and the social, cultural, moral and personal connotations that they carry would therefore have implications for any diabetes self-management programme that has lifestyle change as an integral part of it.

Another issue to be considered is that of culturally prescribed roles and the way in which these not only influence the experience of disease but are also influenced by it. A case-study conducted by Sudhir, Kumaraiah, and Munichoodappa (2003) highlights the importance of the position held by family members. In this study, the father of the patient refused to be involved in the therapeutic process but had the final say in whether or not appointments were kept and therapeutic suggestions followed. This shows that there are certain expectations regarding the roles that could and should to be played by

different people, including the health professional, in connection with the diagnosis and management of diabetes. Deference to the authority of members of society and family according to cultural rules could lead to conflict when it comes up against medical authority with regards to treatment. Chun and Chesla (2004) and Chesla and Chun (2005) assert that the collectivistic social organisation of the Chinese culture means that personal advantage is often relinquished in order to fulfill societal expectations and minimise confrontation with, and impact on, the family and society. With reference to Type 2 diabetes, they argue that this interdependence shapes both the experience and expression of the disease, and diabetes becomes a shared rather than an individual experience with the family playing an important role in both the decision-making process and the direction which it takes. Lawton et al. (2006) also describe how the people of Indian and Pakistani origin in their study felt that family obligations took precedence over the pursuit of individual activities related to the management of their diabetes, such as exercise, and that these constraints are particularly applicable to women. Cultural expectations therefore constrain the way in which individuals can behave if they wish to continue to position themselves as part of the cultural group and this in turn has implications for the way in which both the individual and the family react to physical illness. For participants in the above studies, cultural beliefs can result in a tussle between the needs of the well and the needs of the ill. There are also concerns over the way in which the family of the patient can express feelings of support and care for the sick, particularly when cultural compulsions are at odds with medical prescriptions.

In this way, not only do cultural notions shape the experience and expression of being ill with diabetes, they also shape what may or may not be done to manage it, who can be considered a source of knowledge, support or advice, and who occupies a position of authority with regards to decision-making. So, through beliefs about disease, prognosis, treatment and social roles, cultural understandings and practices would influence positions held with regard to certain treatments and self-management options (Kirk, Weisbrod & Ericson, 2003). However, while cultural understandings and practices influence the experience of disease, they should not be regarded as merely constraining or problematic. Participants in the study conducted by Chesla and Chun

(2005) interpreted the continued involvement of the family in diabetes management to be an expression of caring and protection. Tresslor and Chamberlain (2005) showed that cultural beliefs around food and traditional practices formed a framework for the transformation and renewal of cultural identity, as well as for working through difficulties encountered during adjustment after migration. The loss of traditional systems can be detrimental. In a report on food systems within Native American cultures, Conti (2006) describe how the loss of pre-1880’s traditional food and lifestyle patterns, and the development of a more commercial lifestyle, has occurred along with a corresponding increase in the incidence of diabetes and obesity. They argue that traditional food patterns should act as templates for healthier choices in modern life. Thus the development and preservation of traditional themes can be both beneficial and empowering, as well as an appropriate framework and resource for the management of chronic illness.

The cultural context also provides both structure for the expression of beliefs through language and for the perception of meaning (Kirk et al., 2003). Thus a standard expression in one culture relating to health or illness may hold a significantly different meaning in another culture (Kirk et al.). The representations of diabetes that patients use to understand and explain their illness are based on accumulated personal experience and socio-cultural meanings, whereas the model used by health care professionals is largely a bio-medical or scientific one based on facts and science (Anderson et al., 2000). Because bio-medicine has its own way of talking about disease, such as specific terminology relating to medical tests, encounters between the medical profession and lay people are best viewed as an encounter between two cultural groups, each with their own beliefs about and attitudes towards disease, treatment and the status of the health professional, and their own way of expressing these beliefs. This would also apply to alternative forms of treatment such as homeopathy, acupuncture and acupressure.

These ‘cultures’ are not mutually exclusive and, as Radley (2002) contends, having a greater say in medical matters for patients could mean having to engage more closely with medicine rather than remaining detached from it. Also, social discourse on illness and the ill that draws on idealistic, inspirational representations and portrays the patient as heroic or stoical sets up moral requirements for coping with disease that can

add burden beyond that of the disease (Dixon-Woods, Seale, Young, Findlay & Heney, 2003). Both Chun and Chesla (2004) and Tresslor and Chamberlain (2005) found that talk around the cause of disease often carried with it moral overtones that portray the ill as lacking in self-discipline or having failed to be good members of the cultural group by failing to follow socially prescribed paths to staying healthy. It might therefore benefit the patient under certain circumstances to take up an alternate construction of the disease that is more fitting to their particular situation. Thus the chronically ill person who is reliant on the medical profession for information, validation and/or medical help may find that he or she is required to reconcile different ‘cultures’ in order to make sense of illness in such a way that life in the social world continues while contending with the illness and its medical ramifications.

However, as Weeks (1990) queries, if an individual, through a shared sense of space and belongingness with different groups, is lead to potentially conflicting notions of self, what are the processes by which these divergent loyalties are resolved? Ricœur (2004) and Benson (2001) envision identity as a woven narrative where the self is constantly under creation in a choreography of change and extemporisation with a grounding in what is most relevant to the life being produced. Barry, Stevenson, Britten, Barber and Bradley (2001) in their study observed that patients and care-givers move between articulating the ‘voice’ of everyday life and the ‘voice’ of bio-medicine according to their particular concerns and position. From this perspective, it can be argued that patients not only endeavor to find a place for social representations¹ in medical encounters but that they also work at finding a place for medical representations in the social world. Empowerment for the patient implies them being free to express these choices and create a picture of the disease and therefore of themselves that best fits their own situation.

Anderson and Funnell (2005) argue that patients cede some power and control to the health system in order to gain access to the skills and care being offered by health care professionals. They contend that an empowerment approach means the

¹ ‘Social representations’ is used here as a generic term to typify socially derived understandings and symbols. It is not a reference to social representations theory proposed by Moscovici (1961/1976) where a social representation is a loosely structured network of ideas and images similar to but more fluid than a theory and used to symbolise a knowledge system (Howarth, 2006; Flick, 2000).

development of a collaborative relationship, where patients are supported and allowed to make decisions in line with their own health goals, rather than the imposition of a professional agenda. Funnell and Anderson (2005) also describe the development of an empowerment based approach to assessment and self-management and suggest the integration of clinical, psychosocial, behavioral and cultural issues into a programme that helps patients to make decisions and changes of their own choice in a supportive environment. They also suggest explicitly affirming that '...the person with diabetes is responsible for, and in control of the daily self-management of diabetes' (p.100). This is true in the sense that, regardless of the advice given the person with diabetes by the health professional, when he or she leaves the office, the health professional can exert little control over the actual implementation of self management strategies (Anderson et al., 2000). However this stance ignores the influence exerted by familial and other social forces on the individual and implies that the person with diabetes who does not take control is not engaging adequately in this process. Where patients who did not take *orders* were once considered to be problematic, patients who are unable to take *control* are now open to the same critique.

In some cases, the patient might choose to cede more control and decision making authority to the doctor than is considered, by the medical profession, to be appropriate for an empowerment approach. Participants of Pakistani origin in a study conducted by Bissell et al. (2004) said they felt obliged to defer to the doctor as a person of authority and standing. Bissell et al. states that this attitude can make it difficult for the health professional and patient to enter into a discussion as equals. They caution that this can possibly undermine the concordance model. However, this assumes that the terms 'concordance' and 'empowerment' refer exclusively to decisions regarding the treatment or management of disease rather than to the entire interaction between health professional and patient – including how that interaction proceeds. For the doctor in such situations, following an empowerment approach would therefore mean recognising the transfer of responsibility while leaving open the option for the patient to assume greater responsibility in the future (Funnell & Anderson, 2005). Like all sufferers of chronic illness, people with diabetes need to understand and accept the limitations of their condition and to learn to manage their own treatment within the *constraints* of their

particular structural, social, cultural and economic situations (Royer, 1998) and empowerment in this sense would mean facilitating this development.

For the individual, a part of understanding their situation would involve the reorganisation and acceptance of the self in a way that the reconstruction of meaning and purpose of life overcomes the limitations imposed by the disease (Royer, 1998). However, it is not just social knowledge and beliefs that shape the construction of and the way in which disease can be experienced; the physical manifestations of the disease that the sufferer alone will go through are also a part of the meaning-making process (Fuhrer, 2004). The person with diabetes is caught between a normalising need to preserve lifestyle and self-concepts and the demands of the illness which necessitate the modification of their way of life (Royer, 1998). This purely physical experience of the disease cannot be shared by health professionals or by other members of the social group (Fuhrer, 2004), and regardless of whether change is desired or socially warranted, the demands of the disease itself could force certain changes in the way life is lived. As Anderson et al. (2000) put it, “It’s not that the patient’s life affects his diabetes care, it is that the patient’s life *is* his diabetes care.”(p.70). It is not enough, therefore, just to talk of therapeutic goals but rather to understand the person’s own goals, the constraints they labour under in connection with living life with diabetes, and their cultural and social resources.

According to Lave and Wenger (2005), learning (in this case the mastery of a new perspective of the disease and new activities for managing it) does not exist in isolation but rather is an intrinsic part of social relationships within which this knowledge, whether instructional or experiential, has meaning. This knowledge evolves within social groups and therefore, acquiring this knowledge is a part of acquiring membership of the group and involves a redefining of the individual’s identity a propos the relationships with other members of the group (Lave & Wenger 2005). Therefore the newly diagnosed person with diabetes must learn the rules of the club, both as a person with diabetes interacting with the medical world, and as a person with diabetes continuing to live within particular social, cultural and familial groups.

Thus, adjusting to life with a chronic disease such as Type 2 diabetes involves a process of making sense of various aspects of the experience, such as the impact of the

disease on the body (Radley, 1989). In addition to continuing with activities required as part of daily life, the sufferer must find space for new activities related to the management of the disease. This process is ongoing, because of the chronic and sometimes unstable nature of the disease, and takes place within the constraints of the person’s social environment and the physical limitations imposed by the disease itself (Radley, 1989). Cultural ideas and social beliefs provide a frame of reference from which individuals, their family and their community understand and deal with illness (Radley, 1989). Ideas derived from Indian culture and the social position of being an Indian in New Zealand would therefore provide the basis from which people of Indian origin would reflect on the disease and its management. Therefore, designing an effective and appropriate management programme requires an appreciation of the beliefs, constraints and processes around which the problem of Type 2 diabetes is tackled, negotiated and resolved. To this end, there are several questions that need to be addressed. What do Indian sufferers of Type 2 diabetes have to say about their disease, its cause, progression and management? How is diabetes positioned in their everyday life? What do they feel about consultations with health professionals they see in connection with their illness, and how are their representations held in place, transformed, re-negotiated or defended subsequent to these encounters? The primary aim of this study is to explore these questions while reflecting on cultural issues that might affect the interpretation and experience of diabetes and its management, and the ways in which these empower, constrain and construct the individual.

Method

The study targeted individuals over 18 years of age living in New Zealand who identified themselves as being of Indian origin and who had been diagnosed with non-insulin dependent (Type 2) diabetes. Only people managing the condition without the use of insulin were considered for the study as it is assumed that a treatment programme that has insulin as an integral part of it will subsume a different set of issues.

The study was assessed and approved by the Massey University Ethics Committee. Potential participants were contacted through existing connections in the Indian community in Auckland and through diabetes special interest groups. In addition, the request was circulated through several online ethnic networks that serve as forums for ethnic groups. Although the online forums are accessible throughout New Zealand, the main recruiting initiative took place in Auckland. This was deemed appropriate as 65% of Asian immigrants, of which 27% are people of Indian origin, live in the Auckland region (Ministry of Health, 2003b). All respondents were from the Auckland region. Potential participants were screened to ensure they met the criteria for the study and provided with information sheets containing details of the study. Suitable individuals who expressed continuing interest were then invited to participate. Seven females and five males were recruited. Participants ranged in age from 32 to 77 years of age and identified themselves as being of Indian origin. Most participants were on oral medication (varying doses of Metformin and some other oral agents such as Glipizide) and most reported co-morbidity such as heart disease, high blood pressure and osteoporosis. All were married or had been married and had family members such as siblings and children living in New Zealand with who they were in close contact. Although no restrictions were made regarding the place of birth of participants, most

were migrants from India. Two participants had migrated from Malaysia and Fiji respectively, but identified themselves as being Indian.

Data for the study was collected through individual semi-structured interviews that lasted for approximately one hour. The semi-structured format was chosen to ensure that key issues related to the research questions were introduced while allowing participants the freedom to create their own story. The venue and time of the interview was decided in collaboration with participants; all interviews were held in participants’ own homes. Before commencement of the interview, the researcher reiterated the rights of the participant and allowed participants to ask questions and clarify issues relating to the study. Interviews began after participants had completed consent forms. Interviews were conducted primarily in English though the researchers’ status as an Indian fluent in Hindi allowed for the expression of thoughts and ideas in Hindi.

Through the use of open-ended questions, participants were encouraged to talk about: their understandings of Type 2 diabetes, its causes, progression and self-management; their life with diabetes and their diabetes-related goals; and their experiences with healthcare professionals and their understandings regarding the role of the healthcare professional. For the purpose of the study, ‘healthcare professional’ represents any provider of health services with which the participant had interacted as a result of their diabetes such as doctors, diabetes nurses, dieticians, podiatrists, etc. This was explained to participants. Probing questions were used occasionally to extend discussion and facilitate understanding of the meaning the disease holds for the participant while continuing to support their viewpoint (Flick, 2002).

Interviews were audio-taped then transcribed. Transcription and data collection processes proceeded simultaneously. Notes were made after each interview regarding the overall impressions of the interview and the account given by the participant. A straightforward transcription convention was employed; interviews were transcribed verbatim and pauses, laughs and other vocalisations were also transcribed to obtain a rich picture of the way in which the story was told. The analytic process used principles of Foucauldian discourse analysis and was based on suggestions made by Parker (1992), Willig (2003) and Hook (2001). Both the analysis and reporting process therefore paid particular attention to the self within the broader socio-political and

cultural context and the way in which these contextual systems operate to distribute power and shape individual experience as well as the ways in which the individuals themselves might work to retain control over their life and illness (Hook, 2001).

Initially, interview transcripts were read and tapes listened to several times. This was done to increase overall familiarity with the data, including nuances within each interview. Extensive notes were made during this process. The transcripts were then studied closely and preliminary codes were created. These were then interpreted to build an account of the way in which participants talk about and account for their disease, the actions they take with regard to it and the way in which these ideas serve not only to construct the disease but to construct the individual as well (Willig, 2003). Tapes were frequently listened to during this process to keep the interpretive process grounded in the participants' own voice. The process looked at the way in which participants talked about their life with diabetes and their understandings of the disease, and how these understandings are held in place, re-negotiated, transformed or defended within the context of self-management and encounters with the bio-medical world.

The interviews, the part played by the researcher and the impressions gained during the interview were also critically and reflexively explored during the initial stages of the analysis process. The interview was considered to be historically and socially situated (Fook & Askeland, 2006; Bottomley, 1997). Thus, beliefs held by participants are linked to socially derived understandings, and these same understandings were then drawn on to appreciate both the sense of self produced by the participant, and the social and psychological reality that they construct (Fook & Askeland, 2006; Bottomley, 1997). This is possible because my position as a member of the Indian migrant community implies a shared way of speaking and shared symbolic constructions that arise from a common social history and shared sense of space and origin. Reflecting on the way in which these understandings are used while analysing and interpreting the data served to increase awareness of how they operate in everyday practice and are used to create a sense of self by favouring certain subject positions over others, thus opening up or limiting opportunities for action (Fook & Askeland, 2006). So, for example, the sense that the participant appeared to look on the diabetes experience as being a positive or negative one lead to the question of why and how that sense was created during the

interview. Impressions gained during the interviews were therefore taken as a starting point for the interpretive process, and examining the way in which a particular effect was created during the interview and the way in which this was related to the account given by the participant was an integral part of the analytic process (Fook, White & Gardner, 2006). Critical reflection on the emotions and effects created during the interviews were therefore used to arrive at a greater understanding, not only about the issues under investigation, but also about the way in which these understandings were arrived at (Etherington, 2004).

The way in which the interview unfolded and the way in which participants responded to questions was also taken into account during analysis. For example, certain participants answered "no problem", "nothing much", "no change" and "fine" to many questions and further probing on the topic elicited very little additional information. During the analytic process however, this served to highlight that the questions to which they gave the most detailed and descriptive answers were, for them personally, the most important issues. Further examination led to an understanding of why some questions were cursorily dismissed. So, comments that "nothing much" happens in diabetes are voiced along with beliefs that many coexisting health problems are attributable to old age rather than to diabetes, and that the correct course of action with regards to lifestyle is being followed. In addition to looking at the overall flow of the interview, pauses, laughs and other discursive devices were also used in the analysis as a guide to discerning and understanding embedded issues.

The interviews also made me aware of my position both as researcher and as a social being. Throughout the interviews, analysis and writing up process of this project, sensitivity to the needs and vulnerabilities of the participants and the Indian community was maintained (Israel & Hay, 2006). A few interviews therefore provoked an introspective review of my responsibilities during the research process. Participants who expressed concern about the state of their diabetes and those who described their diabetes as being out of control were advised to contact a doctor, diabetes nurse or diabetes support group about issues that were discussed during the interviews. In one particular interview, I suggested that the interview be terminated as I felt the participant was not physically comfortable enough to prolong it any further. We resumed taping

only after she insisted that she wished to continue. After these interviews, my concerns and actions were discussed with my supervisor.

As Chamberlain (2004) writes, this study could be considered a social exercise in itself. The relationship between the researcher and participant and the way in which this shaped the data and the interpretive process was therefore also considered (Chamberlain, 2004). One interview in particular made me very aware of my position as a young Indian female, the meanings that cultural label carries in interactions with other Indians and the implications it could have in a research situation. This interview took place in the home of the participant, and his wife was present through most of the interview. During the interview, the participant introduced the idea that diabetes might cause erectile dysfunction. This concern had not been expressed in any other interview and had not featured prominently in the groundwork carried out prior to the interviews. The participant then used erectile dysfunction as an example to describe, in the third person, the importance of specialist knowledge in the health professional dealing with patients with diabetes.

In retrospect I am disappointed that I did not engage more closely with this interview as this brief discussion revealed a wealth of information during the analytic process. The participant was allowed to talk and supported through the use of appropriate vocalisation, but I did not work in any way to extend the discussion. Looking back, I believe that my position as a young Indian woman talking to an unknown older Indian man was influential in my discomfort and my failure to develop this particular notion. Traditionally, in Indian culture, certain personal issues are not openly discussed between men and women, particularly if the male involved happens to belong to an older generation. However, throughout the interview, the participant approached questions in a practical and academic manner and informed me that he had already participated in several other studies. This suggests that the participant saw me exclusively in my role as a researcher rather than my social or cultural position.

Being reflexive about the interview process and the way in which the data was obtained helped to refine the data gathering process by guiding the way in which decisions were made and topics introduced in subsequent interviews. Contemplating the assumptions and traditions both explicit and implicit within the interview helped to

develop the account and also to bring cultural assumptions and practices, both mine and the participants, into relief.

Participants made sense of the disease through understanding and accounting for the diabetic body. The discursive production of the diabetic body also served to construct the disease itself. The way in which the body is understood, and the perspective of the disease this provides, becomes the frame of reference for choices made with respect to managing the disease, interacting with others and continuing to live life. At different points in their narratives, different understandings and constructions of the diabetic body were drawn on to describe and explain different aspects of the diabetes experience and to validate and rationalise the various measures that are taken to deal with it.

Participants were able to draw on different constructions of the self that justified and explained the actions they were taking while continuing to portray themselves as good Indians, citizens and family members. This view of diabetes and of themselves opens up access to opportunities to make changes and embrace new behaviors to manage their diabetes. On the other hand, some participants created a picture of a social reality, attributed to ill health or taken up as a moral position, where managing diabetes is presented as being incompatible with their preferred subject position. For these participants, it is not possible to have more than one view of the self and this closes down some management possibilities and limits new practices that can be adopted to manage their diabetes.

Throughout their accounts, participants used the reported word of medical professionals to reinforce their arguments, justify their actions and explain their beliefs. Participant's stories were characterised by a great deal of reliance upon and respect for the medical personnel that they see in connection with their diabetes. In this way, participants built up an account of their life around diabetes and the way in which their values and beliefs drive their decisions and actions.

My findings are presented in the same way as participant's stories were told; not broken into discrete thoughts, but rather as a tangled puzzle that moves off occasionally in unexpected directions while remaining grounded in the embodied person. Therefore the segments in the following section do not represent detached concepts or themes; they

flow into each other to create a complex understanding of the way in which the disease is integrated into the life of the person with diabetes.

Participant's voices are introduced into the discussion in several ways. Words and phrases in double quotation marks are participant's words taken directly from transcripts, and their stories are used to illustrate analytic points. Longer quotes are presented to amplify their voice and enhance the understanding of my interpretation. These quotes have been edited slightly. Some repeated phrases, laughs, sighs and pauses have been removed, as have my own supportive utterances. Every attempt has been made to ensure that the integrity of the participant's thoughts and ideas is retained. For example,

"...and er although I've had the flu vaccine I've had three flus this year...

I: Oh really?

P: already in the last six months and very bad like each time it's been two weeks of coughing and um you know the cough and cold and soreness and all that..."

has been edited to read :

"...and although I've had the flu vaccine I've had three flus in the last six months and very bad like each time it's been two weeks of the cough and cold and soreness and all that."

While the identity of participants is protected, it is acknowledged that within Indian culture, the name holds great significance and reveals a great deal about the religion, sub-culture and history of the individual. In order to respect this, an attempt has been made in choosing pseudonyms to preserve the veracity of the person behind the name.

Findings and Discussion

This section is presented in five segments. The first of these is about the diabetic body. Understanding diabetes begins through describing and accounting for the diabetic body which is believed to be different to other bodies. Diabetes is believed to be potentially harmful to the body. In order to minimise this harm, it is believed that diabetes must be kept under control. The second segment therefore explores and describes the several ways in which the person with diabetes might chose to control the disease and each is validated by a particular belief in its cause and nature. Understanding and controlling diabetes is a complex and contradictory process that involves working out the meaning of diabetes and what can be done to control it. As a result of this process, the person with diabetes is able to construct a picture of the disease and what can be done with it. The third segment explores ideas of normalcy in diabetes and the way in which the person with diabetes constructs a picture of the way in which the disease develops and what can be expected of it. These are not static representations; they are reinvented and developed with experience and further information. All this takes place within the particular social and cultural perceptual system of the person of Indian origin and the environment within which they live their every-day lives. The fourth segment is therefore about the person and the cultural and social aspects of life which might influence the perception of diabetes or the implementation of management activities. Throughout this, the person with diabetes is actively engaged in processing new information, weighing options and defining who they are, not merely as someone with diabetes but as multi-dimensional individuals. The fifth segment draws all other segments together to show that the issues related to diabetes and its management are not considered in isolation. Rather, people with

diabetes are engaged in a working out an intricate impression of what diabetes means for them, for their families and social connections and what opportunities are available to deal with this disease.

The diabetic body

Narratives about the diabetic experience reveal that Type 2 diabetes is viewed as something that *happens* to the body, such as an inability to make insulin or an imbalance within it. There is a point at which the body changes and this comes about in a manner reminiscent of a transformation. There is a clear belief in a before and after, though the point at which this transition occurs is often nebulous. The advent of diabetes within the body causes a change in its health and this makes the diabetic body different to other bodies. The idea of change is conveyed through talk of being “fit” and “hale and hearty” before diabetes and subsequently being concerned about health issues that never happened “before”. The diabetic body is also believed to *feel* different and some participants report that their diabetes was diagnosed after they approached a physician because their body did not feel “normal” but rather “out of synch”.

Making sense of a diagnosis of Type 2 diabetes also requires the re-organisation of understandings surrounding symptoms and their implications where bodily phenomena take on new significance. For example, Mr. Batra describes going to the doctor complaining of numbness in his fingers and toes that he attributed to his current job which involved sitting down for long periods of time. Subsequent tests revealed that he had diabetes and he was informed that the numbness was due to his condition. In this way, previously insignificant sensations take on new, and sometimes unspecified, meanings. The unfamiliar nature of the diabetic body causes the person to “lose confidence” in the body and leads to greater concern about the body where the individual becomes more conscious and more apprehensive about sensations and occurrences within the body. Kierans and Maynooth (2001) saw a similar shift in the arena of somatisation in their study with chronic renal sufferers. Prior to a diagnosis, the individual is not necessarily preoccupied with the rationalisation of physical sensations on the basis of disease. Symptoms of a disease, while suggestive of that disease, can also be explained in several different ways depending on the life experiences and

propensity of the individual. However, post-diagnosis, in the context of bio-medical interactions, bodily sensations are interpreted on the basis of what they mean for the disease (Kierans & Maynooth, 2001).

The person with diabetes is not merely concerned about what might be considered to be symptoms of diabetes and what these symptoms might say about the status of the disease. There is also concern for the way in which diabetes affects the body and the possibility of the condition leading to other health issues. Mrs. Mullah gives the example of feeling a pain in her side. Where she says she would have probably ignored it before being diagnosed with diabetes, she now worries that it might be something to be concerned about, such as a problem with her appendix.

The perceived location of diabetes within the body makes physical manifestation an important part of the way in which the person assesses their diabetes and reacts to it. One way in which the disease is understood and evaluated and decisions made regarding the need for action is associated with symptoms that are believed to be markers of the disease. Some symptoms attributed to diabetes are weakness, fainting, loss of sleep, frequent urination, giddiness and tingling or numbness in the hands and feet. The belief that the disease manifests in a physical way means that symptoms become an important part of the way in which the body is assessed. The number of symptoms, the discomfort they cause, and the impact they have on the smooth functioning of the body become an

Q : Have you ever had any problems that you think might be related to diabetes?

A : No. Frankly I didn't even know that I had it. And even now I think one of the reasons why it's taking so long to really get into the groove is because you feel nothing. I mean I feel... I mean I guess I feel a little tired in the evening which they tell me may be due to high sugar but I feel that I get tired because of the amount that I put in during the day

assessment of the severity of the disease.

Participants felt that they have “no problem” or are “fine” because they have few, if any, of the symptoms they associate with diabetes or if their symptoms are “little problems”, such as tingling or numbness in the hands and feet, that do not impact on their ability to continue with every-day activities. The body is understood through its use

in the course of daily life and therefore, the perception of illness, as Radley (1989) argues, is dependent on the ease with which these everyday activities may be maintained. However, from a health care point of view, sufferers of diabetes can, and often do, remain asymptomatic for several years, and this is independent of biological

markers of the disease used by the medical profession to assess the onset and severity of the disease and the effect it has on the body (Krentz and Bailey, 2005). Being asymptomatic as far as diabetes is concerned allows the more prominent and bothersome symptoms of co-morbid issues to rise to the forefront. More attention is therefore diverted to these issues and diabetes recedes into the background. It is still described as continuing to impact on the body, but ceases to be an issue on its own. The story of diabetes is then told through the effect on the body of these other health issues and this becomes the basis from which treatment decisions are made.

It is also believed that the diabetic body is different to other bodies because it is weaker and more vulnerable and that this impacts on the way in which the body reacts to health threats. In this diabetic state, it is believed that the body succumbs more easily and more often to common illnesses, such as influenza, and that these afflictions tend to be “very bad”. Participants also report an increase in the frequency of unexplained problems such as boils and fungal infections of the feet. The changed nature of the diabetic body is thought to affect the outcome of other health issues. Most participants report some form of co-morbidity, and while

I think I'm more prone to, you know, getting the flu and although I've had the flu vaccine I've had three flus in the last six months and very bad like each time its been two weeks of the cough and cold and soreness and all that. Also I've had the fungal infection on my feet which I've never had before. I don't know what it is and the doctor told me you'll probably be prone to these things because your immune system is down. It went away after some cream that was prescribed but otherwise I'm ok now but this year more than any other years I find that I've had the flu too often I think. So that sort of thing sets me back. I don't know why that's happening.

the onset of these conditions is believed to be independent of diabetes, it is believed that their co-existence leads them to be inextricably linked together. This is partly because the diabetic body is understood to be more prone to complications, such as excessive bleeding. Thus the decision to have surgery to deal with a problem or ease discomfort is evaluated against medical opinion regarding the possibility of increased bleeding. The diabetic body is also believed to be more susceptible to complaints such as glaucoma and gangrene. This means that the diabetic body can potentially be a mutilated body as a result of amputation or loss of certain bodily functions: “Anything can happen, anything... could be a stroke, your kidneys can fail, your liver can go, eyes start getting effected”. Similarly, participants in a study by Ford, Havstad, Brooks and Tilley (2002) also considered diabetes to be disfiguring and associated this feature of diabetes with loss; the loss of limbs, vision, mobility and youth.

Participants also report problems with treatment regimens where medication prescribed for other health issues has exacerbated their diabetes. This means that the treatment of one can lead to deterioration of the other and a decision must be made as to which condition to treat and which to endure. Mol and Law (2004) ask the question, “Which life to live, and which body?” (p. 55). While this question is indicative of the tensions that diabetes triggers within the body, it should not imply liberty to choose (Mol & Law, 2004). Participants described how some control over health outcomes can be lost due to changes that occur within the body. In order to regain control over the situation, various strategies are put into practice that provide an alternate way to deal

I was very well off till about 2 years ago then I developed some lung disease and then I realised that my diabetes was also not being very much controlled. Now the problem was that because of this disease I had to take a lot of steroids. But I took one tablet of steroid and my sugar went up to 500 with only one tablet so I had to discontinue it. Then I had lots of problems and I developed acute pancreatitis with the result that I had to discontinue all my treatment for the lung disease. Then I went in for homeopathic with that homeopathic medicine my diabetes got controlled very nicely. My lung problem it did not get treated, the treatment just stopped right there

with the issue while continuing to function and perform tasks related to everyday living. These may involve turning to alternative medical systems such as homeopathy or a re-ordering or modification of practices. So, anxiety regarding bleeding during surgery has led Mrs. Mullah, who is suffering from a badly healed foot injury, to alter the way in which she walks in the hope that this will avert the need for surgery. For Mrs. Bajaj on the left, the complications caused by the treatment for her lung condition means that treatment had to stop. The untreated lung problem inhibits her ability to exercise to any great

degree and this further limits options for the way in Type 2 diabetes can be managed. Co-morbidity, such as a lung condition, an injury or severe osteoporosis can make it difficult for the individual to carry out activities, such as exercise, related to the management of diabetes.

When asked about the future, participants talk about continuing to deal with the disease the way they have been as long as circumstances remain the same. The diabetic body is regarded as unpredictable where some unknown factor may act to change the course of the disease and therefore the condition of the body. For example, Mr. Singh expressed the belief that exercise is most effective at keeping diabetes under control. He has therefore devised a rigorous exercise regimen that he follows every day and plans to

maintain “as far as possible”. Later in the interview, he confesses that the complication he fears most is amputation. Current medical texts assert that there is an increased risk of gangrene and amputation in diabetes (Krentz & Bailey, 2005) and many participants in this study relate stories of family members who had lost digits or limbs through amputation. The amputation of a toe or foot could possibly compromise the ability to exercise and therefore limit management options in the future. Although Mr. Singh believes in a course of action to manage the disease and testifies that he adheres to it, he also acknowledges that future management of the condition rests on other factors that might be out of his control. This implies the possibility that he may not be able to control the disease in a way that he believes is the best way.

Type 2 diabetes is primarily viewed as something that happens to the body in later life. Accounts of a diagnosis or of severe complications and death in people perceived to be too young are therefore more emotional and accompanied by a sense of disbelief. Participants also believed in the possibility that their condition could worsen with time as a consequence of ageing of the body. The body is thought to get weaker with age and therefore more predisposed to complications and an increase in their severity. There is also the fear that there is an increase in other health problems in the ageing body that further compromises its health and therefore its ability to cope with diabetes. The diabetic body is therefore perceived to be in a fluid state and diabetes is viewed as a dynamic rather than stable condition. The condition of the body can improve or deteriorate depending on the demands placed on it, both by diabetes and by other illnesses or accidental injuries.

The body is therefore the starting point for understanding and exploring Type 2 diabetes. The changes that occur within it remove some amount of control over the body and the future of the disease from the individual. However, along with uncertainty with regards to the future and feelings of limited control over the diabetic body, it is believed that it is possible, to some extent, to keep diabetes “in check” in order to prevent it from getting “worse” thereby returning some power over the course of the disease and over the body to the individual.

Understanding and controlling diabetes

In order to regain some power over the disease and the body, the person with diabetes tries to explain and account for the disease in such a way that certain activities become coherent ways of dealing with it. Participants provided several explanations for diabetes and, though one explanation might be more privileged than others, they were not mutually exclusive. The individual draws on various sources of knowledge, such as bio-medical, cultural or historical resources to create a picture of diabetes that best fits their particular circumstances. In their study on long-term incontinence, Bradway and Barg (2006) show that the meaning of that chronic illness is an amalgamation of individual experience as well as cultural cues and shared understandings of the problem.

The use of the word “suffering” by participants when talking about their diabetes implies being ill with a medical condition. Credence and validation is therefore given to taking on the role of a person with diabetes and to the adoption of management activities because the diagnosis is confirmed by the medical profession. The medical label for diabetes is particularly important because the interviews reveal that many participants struggle with the idea of being diabetic. This is because they do not experience many of the physical phenomena identified in bio-medicine as being symptoms of diabetes. Credibility is therefore given to the diagnosis because it is confirmed in medical settings such as the hospital, often in connection with other medical conditions such as injuries or surgery or during routine blood tests, leading participants to reiterate that it was “the medical professional” who confirmed it and not “anyone else”. The diagnosis creates awareness which can become a starting point for the person to develop a way of dealing with the disease.

Defining diabetes as a medical problem leads to fragmentation or breaking up of the body into component parts. This is compounded by the way in which the medical system is organised. In New Zealand, while the initial diagnosis and treatment of diabetes is achieved at the primary care level by general practitioners, patients are referred onward to several different professionals to deal with screening for and treatment of the complications arising out of diabetes (Ministry of Health, 2003a). In addition, they might also encounter other doctors or health professionals as part of treatment initiatives to deal with co-morbid issues they might have. Thus participants

describe being in contact with several different health professionals, who each deal with one particular area of the body and one set of medical problems. In this way, although diabetes impacts on all decisions that are made in the medical arena, the diabetic body itself is fragmented by the health system during this decision making process. The person with diabetes must then draw this fragmented body together while implementing the treatment recommendations arising out of this process. For the newly diagnosed person with diabetes or for the Indian migrant with diabetes who has just arrived in New Zealand, part of the process of learning how to deal with the disease also involves building an understanding of the medical system on which they are dependent for information and support in order to deal with a disease that has been labelled and diagnosed by the medical community.

With the medicalised view of Type 2 diabetes, it is described using medical terminology such as the word “treatment” to describe its management. This treatment, whether medication or lifestyle change, is “prescribed” by the doctor or diabetes nurse. Progress is monitored by the medical profession in a way that is stipulated by current health policy. The national Get Checked programme entitles every person with diabetes in New Zealand to one free diabetes review per year with a GP or appropriately trained primary care nurse and regular three monthly reviews of HbA1c levels are also recommended (Ministry of Health, 2003a; New Zealand Guidelines Group, 2003). Participants in this study report scheduling these visits with their GPs and also describe the importance of self-checking with a blood glucose meter. The constant “checking” by the medical profession fits in with the picture of diabetes as a medical condition in need of constant surveillance.

The blood is seen as the main part of the fragmented body that is associated with monitoring and controlling the disease. Diabetes is reduced to a number that is obtained through removing blood from the body and testing it in a medical machine. Participants also commented on the invisibility of diabetes in that the person with diabetes often does not look sick. Diabetes has few visible manifestations and is therefore not easily discerned by the undiagnosed sufferer or by other people. The importance of testing and the visual objectification of the body was also reported in a study by Rhodes, McPhillips-Tangum, Markham and Klenk (1999). They found that tests and a

confirmed diagnosis of chronic back pain, another invisible condition, both legitimised the sick role and accorded social recognition to the condition and the problems faced by the person with chronic pain. For the people in the present study, the results of blood testing are a way of knowing diabetes when its symptoms are perceived to be minor or absent. The number that is obtained through testing the blood, that now represents diabetes, is compared to a range set by the medical profession and judged to be “normal” or “in level”, “high” or “low” in comparison. As Karas Montez and Karner (2005) observe in their study, changes in these numbers or levels are not associated with the development of or change in any physical sensations. However, testing the blood, both personally and through the medical system, is one way in which a decision is made as to whether the disease is under control or whether something needs to be done in order to bring the number in line with what is believed to be an acceptable range.

Although Type 2 diabetes is represented as being a medical condition, participants still create their own understanding of the condition to explain what is happening to them and to interpret the information that is provided by the medical professional. Thus diabetes is thought of as an imbalance in the body that is created mainly through an increase in “sugar” causing “high sugar levels” or a greater than normal “glucose value” in the blood. In fact, the words “sugar” and “diabetes” are often used synonymously and diabetes is often referred to simply as “my sugar”. It is believed that the intake of sugar will increase the level of sugar in the blood and the associated approach to controlling diabetes therefore involves limiting the amount of sugar in the diet. Dietary sugar is thought of in several different ways. The first one is “direct sugar”. This is the most prominent discursive construction of sugar and, in this case, dealing with diabetes involves limiting or discontinuing the use of sugar in tea, soft drinks and the intake of chocolate and other foodstuffs believed to be high in sugar such as ice cream, muffins, biscuits and cakes. The sense of taste appears to be very important in making this decision of what is the “wrong thing” to eat and greater emphasis is placed on foods that

I don't eat anything with direct sugar. I don't have too many fruit juices. I used to have a bottle of coke a day. All that is out. I do have a little chocolate and ice cream but that's on rare occasions, not on a daily basis like I used to. I've got a big sweet tooth so I used to enjoy all this. Now I just don't eat chocolate and stuff except maybe on the weekend

taste sweet. The prominence of sugar and sweetness can be traced to the Sanskrit word for diabetes, *Madhumeha*, which can be loosely translated to sweet urine (Tiwari, 2005).

Another, less prominent, way of thinking about sugar is the way in which it might be present in other items in the diet such as fruits and vegetables, rice and other carbohydrates. Participants are also concerned about the “fried stuff” and the “fatty things”. They are concerned about excess oil and fat for several reasons. This food group is believed to have a detrimental effect on many of the other health problems they suffer from such as high cholesterol. Because these issues are believed to affect the way in which the body is affected by diabetes, it becomes necessary to deal with them appropriately as well and to combine their management with the management of diabetes. This food group is also believed to enhance the likelihood of an increase in weight and because one of the causes of Type 2 diabetes is believed to be obesity, participants are concerned about their weight. Therefore while the consumption of sugar is believed to have a direct link with sugar levels in the blood, other aspects of the diet are believed to have an indirect effect on diabetes and therefore also need to be controlled. In Indian medicinal systems, such as Ayurveda, a strong link is described between nutrition, digestion and diabetes (Tiwari, 2005). In keeping with this, the diet was more prominent in talk by participants around the causes and management of diabetes.

This link between the diet and Type 2 diabetes results in several strategies to keep sugar levels down. The amount of sugar consumed is reduced. Instead of sugar, artificial sweeteners are used and the switch is made to diet varieties of soft drinks. There is also the use of what are believed to be healthier varieties of certain foods such as “good Burgen bread” instead of white bread or wheat chapattis instead of bread. In this way, not only is the disease reduced to a number, the activities used to manage it are also medicalised. Whereas earlier participants say they might have been satisfied as long as “the picture looked good” on the carton, food is now reduced to labels, contents and quantity. Because of the “harm” that diabetes can cause, the health professional also becomes the protector who warns and educates the person with diabetes against potential dangers in the form of the wrong types of food and prevents him or her from being “fooled” by misleading food labels. In line with the findings by Tresslor and

Chamberlain (2005), certain foods such as *methi* (fenugreek), *karela* (bitter gourd) and chillies are used as medication to “control your sugar”.

An aspect of being able to follow a management plan, particularly with regards to the diet, is being able to set and keep personal limits. Going beyond these limits, such as overindulging food and drink, is constructed as “greed”. Being able to say ‘no’ is therefore described as an important part of controlling diabetes through altering the diet. Saying ‘no’ in this sense refers to being able to control personal impulses rather than being able to resist the imposition of another’s will. Ecks (2004) draws a link between ancient Indian medicinal systems, the role that diet plays in health and illness, and the idea of body discipline. According to him, food and the stomach are traditionally believed to be crucial to the active pursuit of health. In order to manage the diet and preserve health, control over the body’s cravings becomes pivotal (Ecks, 2004). There is therefore cultural wisdom, grounded in ancient texts, which suggests that the inability to adequately control impulses leads to ill health. These beliefs are reinforced by more recent political and social writers, as well as practitioners of traditional medicine (Ecks, 2004). Participants tried to form a link between past or present indiscretions, such as their diet when they were children, a “bad sweet tooth” or the “love” of food, and the development of diabetes or their inability to control it. Personal inclination becomes problematised rather than a type of behavior (Crossley, 2003). In order to bring diabetes under control, participants feel they must overcome these “problems” and learn to be satisfied with a small amount of food, turning down things they know they should not be eating. They joke about “temptation”, of “stealing” sweets and chocolates when no one is looking and of “watchdogs” who keep an eye on their sugar consumption.

Q : After your diagnosis of diabetes, has your life changed?
A : Nothing particular, except taking medicine. Food habits are very simple so there’s no point in it. We are living simple life. I am retired DAG in police, but nothing... hardly used to take any meat once a month that too at parties. We are not much meat eaters so not much use of eggs etc. Sweets, you know, we don’t buy. I, you know, stole them when nobody’s home (laughs) If they are there I will eat. In the childhood we used to take lot of gur (Jaggery)

The use of the word stealing elaborates the idea of the self in need of monitoring and policing. Theft and greed are both concepts with very strong moral bases to them and carry a thread of personal responsibility and impulse control. This moralistic view of health means that the assignation of responsibility for the onset of the disease includes a measure of the character of the individual (Crossley, 2003).

The account of the diet in diabetes constructs the person, not only as health-conscious, sensible and vigilant, or as a good patient following doctor’s orders and working hard to manage their condition, but also as a simple person with simple needs and simple lifestyles. Many participants, particularly older ones, declared that they ate little meat, consumed no alcohol and were hardworking, productive members of society. India has a long tradition of revered leaders, philosophers and writers, such as Gautama Buddha, Mahavir and Gandhi, who preached minimalism and self-control as a way of life in order to preserve health in a holistic sense that incorporates moral health as well as physical health (Ecks, 2004). By constructing themselves in this way, participants are aligning themselves with cultural ideas of health and healthy practice. People of Indian origin in New Zealand live in a very different environment to that of Gandhi and modern Indian society has itself undergone many changes. However, vestiges of the qualities that Gandhi and other great leaders aspired to are still apparent.

This idea of personal responsibility is emphasised in another way. Participants

My brother is so bad that now he’s lost a toe. My sister was so bad she has already had a stroke and also that’s the combination of diabetes and high blood pressure and lifestyle and I could see for myself that she was not managing. The more I told her “you’ve got to do something”, the more she would be stubborn and do the things that I tell her not to do. Like I tell her, “Don’t eat so many of the wrong things”, but she would do it in front of me almost to annoy me

reiterate that the actual management activities that doctors recommend are not difficult and that all it takes for diabetes to come under their control is for them to make the effort to control it. Failure to bring diabetes under control in this way is blamed on an inability to “focus” and the person with diabetes who chooses not to do the “right thing” is labeled “stubborn”. In this sense, Type 2 diabetes is a very personal disease. Participants were prepared to take ownership of the disease and responsibility for future prospects. Even though Type 2

diabetes is regarded as a medical condition, it is not believed to be the responsibility of the medical profession to cure or manage the disease but for the individual to be “careful” and thus attempt to change the course of the disease. This means that cultural beliefs of appropriate behavior align easily with the bio-medical view of diabetes, which is that of a chronic condition managed mainly through the diligence of the patient (Anderson et al., 2000; Funnell & Anderson, 2005).

Although diet control and self-control are believed to be important in the management of Type 2 diabetes, there are other aspects of the consumption of food that play a part in whether this control is achieved. In parallel with findings by Tresslor and Chamberlain (2005), Chesla and Chun (2005) and Chun and Chesla (2004), pleasure, enjoyment and the opportunities for cultural or social affirmation that food provides plays an important part in the implementation of dietary change and there are some foodstuffs participants say they "cannot", or find difficult, to give up. In addition to foods that should and should not be consumed, the quantity that is consumed is believed to be significant and participants talk about reducing the quantity of both sugar as well as the general amount of food consumed. The timing of the meal is also deemed important. It is believed that breakfast, lunch and dinner should be eaten at fixed, regular intervals and an interval should be allowed between eating and retiring to sleep. However, taking regular breaks for meals or eating meals at fixed times during the day can be difficult in certain occupations, particularly when the job entails shift work. Rohan confesses that he sometimes skips lunch and then eats a big meal after he returns home in the evening. So, though participants can describe what they believe are appropriate eating habits, they admit that they are sometimes unable to persevere with them for reasons they believe to be beyond their control.

The idea of using dietary control to manage diabetes is understood to be in the nature of a balancing act because too much of a reduction in sugar or quantity of food consumed can lead to low blood sugar causing fainting and coma. Thus the occasional consumption of the "wrong things" is legitimised and made acceptable in the context of keeping these unwanted complications at bay. The amount of control over sugar that is needed to maintain blood sugar levels at prescribed target levels is also used as a measure of how bad the disease is within the body. The level of dietary change required to bring the disease under control becomes a measure of its seriousness. A minimum effort at control, such as discontinuing the use of sugar in tea, that results in steady blood sugar readings implies a positive appraisal of the state of the disease; the greater the number of changes required, the worse the state of the disease is believed to be.

Exercise is also believed to be effective in controlling diabetes. Although, as mentioned earlier, the development of diabetes is related to nutrition and digestion,

Ayurvedic teachings also suggest that it is aggravated by an imbalance in the utilisation of energy (Mrinal, Mrinal & Mukherji, 1995; Tiwari, 2005). Exercise is therefore believed to work through balancing food intake with activity and the maintenance of homeostasis within the body, a priority in both the Ayurvedic and Unani medicinal systems. However, exercise is mainly described by participants as a form of treatment that is recommended by the doctor. Like food, exercise is also medicalised and participants talk about following a prescribed amount of exercise. Like diabetes, the exercise used to combat it is reduced to a number and measured objectively through the use of mechanical devices such as a pedometer. Therefore participants talk about exercise in terms of number of steps per day, number of kilometers per day or number of minutes per day. There is tension created when the individual tries to

I do walk around a lot during the day. They gave me a pedometer to see if you can do ten thousand steps and I used to do ten thousand easily as part of my daily work. So ten thousand on a week day was no problem. The weekends used to be about three thousand or so. I used to go for a walk, now I've bought an elliptical trainer (laughs) it's been there for about eight months or nine months. We're hanging clothes on it.

integrate the objective, medicalised view of diabetes and its management requirements within the activities required as part of daily life. For someone whose job involves physical exertion or walking long distances, fitting in the required amount of exercise during the work day does not require any extra effort on their part. For others, it involves scheduling exercise around other activities

required as part of the day and overcoming obstacles such as the weather. For others labouring under disabilities that inhibit their ability to exercise, it involves doing whatever is possible or abandoning exercise as a management option.

The classification of Type 2 diabetes as a medical condition justifies the use of medical methods to monitor and control it: a biomedical solution for a biomedical problem. The use of medical apparatus, such as the blood glucose meter, becomes appropriate and indeed necessary to monitor the disease in this way and the use of medicines is a fitting method of control. All participants report using varying doses of Metformin as well as some other oral agents. The medicalised view of diabetes implies that medicine is a crucial component in the endeavor to control it. Contingency plans to deal with adverse situations, such as a high blood sugar reading or an event that leads to excess consumption of the wrong kind of food, include temporarily increasing the daily

dose of medication. The amount of medication also becomes an indicator of how severe the disease is. The state of the disease is assessed as not so bad if it is controlled by “only” one tablet and a reduction in the dosage of medication required implies that the person is winning the struggle for control over the disease. On the other hand, an increase in medication signifies inadequate control and increased severity of the disease.

Several participants have a reduction in medication as one of their goals for the future. Using this reasoning to assess the state of the disease, the worst possible scenario for Type 2 diabetes is the need for insulin. Mrs. Khan on the right describes, with a sense of pride, her triumphant fight to prevent being put on insulin. Being on insulin is described as being “very heavily diabetic” and is associated with stories of failure to keep diabetes under control with life-threatening consequences. As argued by Kierans and Maynooth (2001), medicalisation provides an understanding of the disease by organising the course of medical interventions, as well as organising physical sensation and its relation to the progression of the disease. Thus the activities and medications used to manage Type 2 diabetes become a way of charting progress and control.

I had some blood tests and they told me my diabetes level was not good. So I went again on a diet and then I had some personal problems and that was the worst shock of my life and I went in a deep depression and the diabetes level kept on going up and it went up to 20 which was not good I was having a lot of headaches and sleepless nights then I went onto anti-depressants. Then my daughters got married and I started living with them and I couldn't manage my diabetes so well. Then I was put on heavy dose of metformin which was 1000 in the morning, at lunch time and in the evening with glycoside it was 120 in the morning and in the evening and on top of that I had hypertension and also antidepressants and sleeping pills. (description of further personal problems)... and that was the worse time. My diabetes level went in 20s because I was unable to manage it and I think stress gives a lot of diabetes. The level of my diabetes was not going down and that was the maximum dose of the medication anyone can take. And then I got this house and before coming here my GP said I have to go on insulin. I told her you just give me one month's time and I will show you how I will improve my diabetes and I didn't take any meat I became a complete vegetarian and all wheatmeal stuff and before that my diabetes level was about 16 and after 6 weeks I went back to the doctor and told her I have been testing everyday and its between like 7 and 6 and in the test it comes 7.2 and then I had to cut down my tablets.

In parallel to the people in the study conducted by Karas Montez and Karner (2005), participants often presented diabetes as an entity with attributes of its own. Mr. Duggal describes how his diabetes was “fluctuating” but has now been “steady” for the past three months. He describes this as, “...now it is behaving”. Discourses of control problematise the disease and separate it from the person, placing it outside the individual, so that the existence of variance and tension between the disease and the individual are understandable (Salmon & Hall, 2003). Unmanaged diabetes is

considered to be "aggressive" because of the potential harm it can cause to the body. In order to resist this unpredictable antagonist, the person with diabetes must be ever vigilant. The fight for control is described as "hard work" with "no time to slip". Thinking about the latent potential of diabetes in this way invokes images of it as a hostile and destructive force. For this reason, several participants admit that their diagnosis was an emotional event where immediately "all the bad complications come to mind". The objective, practical approach of the health professional is helpful in this situation. The health professional is a source of encouragement as well as the source of explanations for the changes the person with diabetes might be experiencing.

Participants who report close relationships with their doctor or diabetes nurse and

They've been after me, you know? In fact one reason why I keep going every three months is because every time I go, I get that urge to then control it. And it's nice to see that other people are taking care and bothered as well. So that gives you a little more... they are so concerned. I mean they keep drumming it in every three months how it can harm your organs. They tell you how to read those labels behind all the food, tell you which ones to buy which ones not to buy. What is good, what is not good. They actually keep boxes in the units so you can see which cereals are good, which this is good, which that is good. And how not to get fooled by low this, low that. Because low sugar could mean high fat. They do it quite practically they're quite good. Earlier I wouldn't even give two hoots. This looks tasty, fine. But now I do look behind and check everything I buy for myself. At least I'm aware. Earlier I used to just buy if the picture looked good

regular three month check-ups, are associated with more optimistic narratives with greater optimism about the future, a more positive sense of self and greater confidence in their ability to control their diabetes. They describe feeling supported and motivated. So, the close medical links that the medicalisation of diabetes engenders can be beneficial to the person with diabetes.

Furthermore, the medicalisation of the body following the construction of

diabetes as a medical condition can also be advantageous to the person with diabetes.

Constructing the disease in this way can be a source of reassurance and relief. The connotations carried by some social or cultural explanations of diabetes or its complications, such as erectile dysfunction, could make the biomedical construction more attractive. With the biomedical construction, the condition ceases to be a reflection of the person or of his age and it is possible to distance the self from the problem by medicalising rather than personalising it.

In addition to viewing Type 2 diabetes as a physical disease with physical causes, it is also viewed as a possible consequence of excessive stress. Participants felt

that “mental condition” or “stress” can also cause a rise in sugar levels or exacerbate the severity of the condition. This view is supported by traditional Indian ideas where health is considered to be a balanced state of the body, the mind and the spirit and a disruption in any of these elements causes the person to become ill (Mrinal, Mrinal & Mukherji, 1995). The goals set in relation to overcoming this problem relate to “controlling stress” by working towards a better quality of life, scheduling rest and leisure time, creating a more positive frame of mind and, for some, turning to a more spiritual way of life for peace of mind. However, achieving these objectives is problematic and overcoming stressors can seem impossible. Mrs. Mehta has diabetes and several other serious medical conditions. She worried about mounting medical bills. She feels the stress is making her sicker but can see no way out of her financial trouble or her chronic ill health. Here, being ill and all that it entails creates a vicious cycle of anxiety and stress.

In these accounts of diabetes, an association is created between lifestyle issues such as diet, exercise and stress, and the development and progression of diabetes which makes the individual culpable for the development and responsible for the management of the disease. Part of the meaning making process for participants in a study conducted by Kierans and Maynooth (2001) also involved resolving the issue of why they developed renal problems. They felt that the development of their condition was linked to bad lifestyle choices such as smoking and drinking and, when unable to make these connections in their own lives, struggled to understand the origin of their health problems (Kierans & Maynooth, 2001). For the people with diabetes in this study, one way of resolving this conflict is the belief in a hereditary link. The representation of diabetes as a hereditary disease removes some of the responsibility from the individual, as developing the disease becomes a question of when it would develop and not if it would develop. All participants were convinced of a link between a history of diabetes in the family and their diabetes. They describe having a “very bad family history” or about having “inherited” the disease from a parent. This belief is further ratified by enumerating the number of people in the family with a diagnosis of Type 2 diabetes; the greater the number, the stronger the case for a hereditary link. In this way, participants

talk about not having “acquired” the disease for themselves but rather having inherited it.

The portrayal of diabetes as a hereditary disease allows for the exoneration of the person. Instead of being a result of the actions of the individual, responsibility for the development of the disease lies with factors beyond the individual’s control.

Participants are therefore able to continue to talk about having led a simple life, of not overdoing food or drink, of exercising regularly and essentially doing the “right things”. They are able to continue to define themselves as conscientious, healthy people while accounting for a disease, the development of which is linked to divergent health behaviours. They describe diabetes as having “caught up” with them despite having done the right thing. According to this conception of diabetes, doing the right things is not enough to prevent its development; the most that can be hoped for is to delay onset or

I thought I was keeping myself pretty well because I was very much into my exercise and walking everyday. Although I had a sweet tooth I didn’t overdo it and I joined the gym. I was doing all the basic right things. But it caught up with me eventually. I think the way the doctor described it is if I hadn’t been doing all those things I probably would have got it earlier maybe ten years earlier or maybe more aggressive. I was pretty conscious that it could happen to me. But when it happened it was a shock anyway. God, you know, (laughs) I did the right things... But that wasn’t enough

commute aggressiveness. The removal of some responsibility for the development of the disease from lifestyle issues also allows for the implementation of small changes in lifestyle and the use primarily of medication to manage the condition. While the belief in the need to keep the disease in check remains, the strategy to deal with it changes.

Another aspect of the inevitability of diabetes appears in talk by older participants who attribute many of the things that happen to them as being a part of the ageing process and therefore a normal part of old age. They appeared to be quite indifferent towards their diabetes and accepting of it as part of life. They describe minimal changes in lifestyle. Constructing Type 2 diabetes as a consequence of old age or attributing symptoms to old age rather than disease allows for the acceptance of changes within the body as a normal part of the ageing process. It also justifies the implementation of minimal changes in lifestyle simply because the condition and symptoms are anticipated and acceptable and therefore warrant the minimum amount of change to an existing way of life. Clark and Asimakopoulou (2005) contend that the onset of the symptoms of diabetes in older people with diabetes is often gradual and less

visible because they appear against a backdrop of other symptoms which are a part of the ageing process. Prochaska, Keller, Leventhal and Leventhal (1987) report that older adults are more likely to attribute mild symptoms to the ageing process rather than to disease, and as a result, to report less emotional distress.

The body in diabetes becomes a work-in-progress with constant fine-tuning required in order to maintain the disease at what are considered to be acceptable levels.

It's just something that I've got to live with. For me it's so be it and it's not going to worry me. I accepted it. I said, "Now how do I get out of having medication?" I really I did lose a lot of weight and my levels came down and then once I realised I could do it, I think then you just ease off. You say "I can easily do it whenever I want". The medication has just gone up a little, the dosage is gone a little higher. I'm still determined to get off but I have to really... it's all me, I've got to ...If I can get off medication, it means my lifestyle has changed and my body is handling the breakdown of sugar properly. If I don't change my lifestyle there's no way I'll get off that medication. My doc was telling me last time, 'cause I have these relapses every now and then, so he was telling me "This is not something where you can have a relapse at will." Its something you have to handle all your life for the rest of your life it's not going to go away.

Management of the disease fluctuates and power over it ebbs and flows. A visit to the doctor or diabetes nurse provides affirmation and motivation which increases the sense of power or control over the disease. An aberrant blood sugar level or other occurrence that increases concern about the complications of diabetes leads to increased surveillance and tighter control while setbacks such as periods of illness can limit the performance of management activities and some control is then relinquished.

The endeavor to control diabetes entails working out the meaning of diabetes, what can be done to deal with it, and how it is assessed. Bio-medical explanations for diabetes are integrated with cultural understandings as well as experiential knowledge gained through personal experience and exposure to the experiences of others. While one explanation might be more privileged than others, they are not mutually exclusive and participants draw on all of these at various times to justify and explain the measures being taken in response to having been diagnosed with Type 2 diabetes and, while the predominant construction of the cause and origin of diabetes provides the main drive for the way in which diabetes is managed, participants use a combination of strategies to manage the condition. Efforts in managing this disease should therefore not be assessed exclusively in view of alignment with biomedical recommendations. Management activities must be shaped to fit within the constraints of the individual's daily life. Everyday activities must be restructured in

order to meet the challenges and limitations of the diabetic body. While the tasks remain the same – eating, drinking, walking, working – there are changes in the way in which they are enacted. As part of the process of adjusting to diabetes and formulating ways to manage it, the individual is also actively engaged in the composition of personal characteristics and in aligning themselves with various social groups. Therefore any activity carried out as part of this process, whether part of a recommended treatment regimen or not, *is* the self-management of diabetes (Hwu et al., 2001).

In this way, the attempt to control the disease is viewed by the person with diabetes as a never ending struggle that will be fought every day for the rest of his or her life. The disease becomes a part of the person (in contrast with a disease that must be cured and removed from the body) and part of every decision making process. The observation and analysis of diabetes and the diabetic body and the process of bringing them under control depends on a judgement of what can be expected of the diabetic body and therefore necessitates the creation of a coherent picture what can be considered normal for a person with diabetes.

So, what is normal?

Managing Type 2 diabetes implies that the person with diabetes is hard at work endeavoring to control the disease in order to keep it in check and minimise the effect it has on the body. In order to monitor the level of control and to monitor the progress of the disease within the body, the person with diabetes forms a frame of reference for the disease. This process involves working out what can be attributed to diabetes and what is independent of it, which in turn allows the person with diabetes to set the limits of the disease. Fixing the boundaries of diabetes is used to create a sense of what can be expected in the future. So, for example, the belief that the immune system is depressed in diabetes implies that the rate of minor infections, such as fungal infections of the foot, will increase. When the person with diabetes experiences an increase in these infections, they are worrisome but also accounted for.

Participants were able to talk about the idiosyncrasies particular to their own diabetes experience, such as the precise site of a recurrent boil or a particular reaction when their sugar levels are not stable. Thus over time, the transformed body begins to

become more familiar and the person with diabetes is able to create a new understanding of normalcy in diabetes that incorporates the distinctive nature of the way in which they experience diabetes. Working out is normal for diabetes also provides a measure of what can be controlled and what cannot. This allows for and explains the failure to control certain health issues or avoid certain complications. However, unlike the biomedical construal of normal that refers to fixed parameters, the complex means by which normalcy is defined means that it is an expression of the individual's negotiated understanding rather than of commonality with other people with diabetes and the picture that emerges is gradually built upon.

While participants used the biomedically promoted idea of norms for their illness, they are able to organise their understanding of the disease in a way that best fits their own experience. This is because health outcomes are not the only issue of importance to the person with Type 2 diabetes. The picture created of the disease has several aspects, such as a list of symptoms or possible changes within the body and a particular path the disease is expected to take. It also incorporates ideas on the impact the disease will have on the ability to continue with daily life and social activities. In parallel with Rehm and Bradley (2005) and Gantt (2002), the standards ascribed to normalcy are flexible and largely specific to the individual's own experience where issues, such as co-morbidity, may influence whether feelings of normalcy are realised.

In order to produce this image of what is expected of diabetes, the individual draws on external sources for information and advice. Health professionals are considered to be "experts" regarding various aspects of the disease. Guidance is also sought from other people with diabetes regarding "what they're doing and how they're doing it" creating shared understandings of the form the disease takes, of options to deal with it and of the location and availability of resources. In addition, the individual relies on personal experience to get a sense of *their* diabetes and the way in which their body is affected by it. They interpret particular bodily sensations, such as "giddiness" or "headaches" as an indication from their body that "something is wrong". These are construed as signals to initiate some form of remedial action, such as taking medication or tightening control over the diet. The assessment of what is normal for diabetes is also based on the ease with which everyday life is able to proceed and, through a form of

self-experimentation the person will observe and evaluate for themselves the activities that will raise or lower their blood sugar levels. Arbitrary decisions are also made regarding what is “too much” or “too often” and certain characteristics are more

When the diabetes you get it you can feel tired very fast. Breathlessness is also there sometimes and you feel giddy when it is little higher you can immediately make out that it has increased. And you feel thirsty all the time. These are the signs and symptoms, and when they do the testing of the blood then in the blood they can find out. And specially when you eat something sweet then also little bit effect is there on your range of diabetic count that we do. So immediately you make out that you have to change the diet and eat less salt, eat less sugar. In the cold season, your lips get dried up fast, your tongue becomes dried up fast and the mouth becomes dry. So immediately you have to take some water and all that. So from that we can make out that diabetes is again not normal. And secondly I can make out when my eyelids starts shaking. That is the sign that I make out so then I take my pressure tablet and my diabetes Metformin

acceptable in the diabetic body than others.

So it is tolerable to have a tingling sensation in the feet, but having a toe amputated is undesirable. Thus, even though diabetes is considered to be problematised in a medical manner, there are still ideas of a *healthy state* within diabetes. One question the person with diabetes struggles with when trying to understand diabetes and chart the progression of the disease is this; how much has the body changed and how much of the change can be attributed to diabetes? Would certain health problems have arisen had the person remained free of diabetes? This question is often made

more difficult because of co-morbid conditions that increase the amount of somatic sensations within the body and make it difficult to sort out the sensations that are attributable to diabetes.

Another way in which the people with diabetes in this study uses the expression “normal” is to refer to the person without diabetes and the person before diabetes. This is held up in contrast to the person with diabetes in an effort to evaluate how much of their bodies and their lives have changed. According to Wellard (1998), in the context of chronic illness, the focus in bio-medicine is to maintain a state of health that is as close to normal health as possible. This focus is apparent in talk by the participants in this study. When diabetes is perceived to be under control, the diabetic body is thought of as “normal”. This body has no or few overt symptoms of diabetes and therefore cannot be distinguished to a great degree from the body without diabetes.

A lifestyle that closely resembles that of people without diabetes is also described as being “normal”. This can be interpreted as an attempt to reiterate that,

despite their disease, they are ordinary people with dimensions beyond their position as people with diabetes. However, as Gantt (2002) and Rehm and Bradley (2005) argue, this should not be construed simply as a form of denial. Like the participants in Gantt’s (2002) study, the participants in this study were able to describe precautions, concerns and the effect that diabetes has on their lives. The condition and its potential to cause harm are therefore acknowledged and confronted, as are differences between the lives of people with and without the disease. The idea of a “normal” lifestyle is therefore considered and evaluated by participants within the context of the perceived state of the disease rather than independent of it. When the state of the disease is believed to warrant few changes, a lifestyle similar to that of people without diabetes is evaluated as acceptable. However, when the disease is perceived to be serious and demanding action, the retention of this “normal” or pre-diabetes lifestyle is seen as a refusal to accept and adopt measures to deal with diabetes. In this way, the idea of normalcy in lifestyle is used both as a way of assessing the disease as well as a way of critiquing the person with diabetes.

The normalisation process in diabetes could also be viewed as an approach to life with diabetes that involves an affective shift. It appears to entail the acceptance and incorporation of management activities, changes in the body and the limitations imposed by diabetes into the daily routine of life. While the body is still under surveillance to ensure that the status quo is maintained, the activities required to deal with it become natural and habitual. Munira describes this as a progression from “Why me?” and “What am I going to do?” to “I can live with this”. This shift is more apparent in interviews with participants who describe their diabetes as being under control. These stories recognise the natural, positive aspects of life with diabetes and include descriptions of how the individual has engaged with the disease and actively worked to deal with it and account for it. The changes to be made are assimilated into practice, making the self-management of diabetes “a part of life”. However, there are several impediments to the adjustment to diabetes and the incorporation of management activities, such as severe health problems and financial and work constraints. The way in which the person defines themselves as a result of the social and cultural relationships they cultivate, and the way in which this either opens up or shuts down opportunities for

action, is also associated with whether the management and control of diabetes was described subjunctively or affirmatively.

Being a person with diabetes

This analysis began with the way in which the diabetic body is described and understood and has focused thus far on the physical things that are done to the body in order to manage the disease. Throughout this discussion, the sufferer has been referred to as the *person* with diabetes. This is because the diabetic body is not an object to be manipulated dispassionately. While the material aspect of the body is undeniable, we are also able through our embodied actions, to convey our conceptions of cultural tradition and social circumstance (Radley, 1998). A deeper, richer appreciation of the way in which diabetes is understood and accounted for therefore requires reflection on the person behind the disease. Furthermore, social and cultural perceptual systems form the basis from which the physical world, and therefore the body, is interpreted and understood (Benson, 2001). Thus the meaning of the body is both shaped by and shapes the world as we know it and the feeling of being Indian and the position of being Indian in New Zealand can configure the diabetes experience in several ways.

As Mol and Law (2004) explain, the body can be explored and known both objectively and subjectively, both communally and privately. The body is not merely material, it is also sentient and the symbolic medium through which the individual signifies and establishes social identity (Radley, 1998). The interviews show that the diabetic body is displayed through the actions that the person must perform as part of dealing with the disease. People with diabetes behave differently to others and therefore draw comment: Shaheen remarks, “...they don’t understand why I say no to things”. It is therefore not possible to merely act. The communal ordering of the body means that these actions have to make sense to others in social encounters. The person with diabetes is therefore forced to declare themselves, both through deed and word. It is believed that this declaration might indeed be necessary for the safety of the person with diabetes. The day-to-day management of the disease is believed to be the personal responsibility of the sufferer. Nevertheless, he or she can feel dependent on the alertness of family, friends and colleagues in case a critical, life-threatening situation, such as a

hypoglycaemic episode or coma, develops. However, the construction of diabetes as a personal problem can make the decision to confide in others difficult.

In dealing with Type 2 diabetes, it is not just the body and the disease that is scrutinised and assessed. The inclusion of the lifestyle in diabetes management plans means that the individual’s way of life, and all the activities and social relationships that it encompasses, is placed under scrutiny and surveillance. Depending on priorities and beliefs, some aspects of daily life are amenable to change while others are not.

Two particular stories in this study exemplify diametrically opposite approaches to dealing with diabetes and the social assumptions, beliefs and situations that limit or extend the potential for action. Both participants are married women with children and work outside the home. Munira describes scheduling time for exercise, has implemented several lifestyle changes and considers her diabetes to be under control. She continuously states that she has taken the opportunity to make “positive” changes in her life and that she “takes care” of herself better. Consequently, she feels she now has a “better quality of life” in contrast to life pre-diabetes when she was “...just trying to survive one day at a time”. Theresa, on the other hand, would like to control her diabetes but has found it difficult to persist with a diabetes-care routine. In contrast with Munira, she feels she is constantly “fighting for time”. Theresa says that her kids and her home come first, that she puts her needs “on the shelf” and describes her daily routine mainly through the routines of her husband and children. She says that though her diet is not optimal as far as her condition is concerned, she makes sure her kids eat food that is both healthy for them and that they like.

Through drawing on self-sacrificing ideals and by telling her story through her family, Theresa is identifying herself as a good mother whose primary concern is the good of her young family. Theresa is able to recount the discourse of the good diabetes patient who tests regularly, takes medication as prescribed, eats the right food at the right time, exercises regularly and makes every attempt to take care of themselves and their body in order to minimise the impact of the disease. However, though she is familiar with this discourse, the good mother and the good person with diabetes are believed to be incompatible as the first is perceived to be other-focused while the second is self-focused. This therefore limits the things that she can do in order to manage the

disease. Munira, on the other hand, is able to adopt the perspective where managing diabetes, and therefore fulfilling her own needs, can be constructed as making “positive” changes, taking control of her own life and health and taking care of herself *better* rather than neglecting the needs of others.

Through drawing on particular discursive resources, the individual creates various ways of being and, within that particular context, certain behaviors become legitimised (Drewery & Winslade, 1997; Willig, 2003). Munira has allowed the possibility of a social way of being where it is possible to have different constructions of the self that can be taken up when needed. This opens up avenues for new practices, such as those required for managing the disease. Theresa, on the other hand, subscribes to social convictions that limit the way in which the self may be conceptualized. This limits the adoption of new practices while justifying those that are carried out, such as her focus on home and family. Through adopting different subject positions, these two ladies have arrived at very different ideas of the options available for the management of Type 2 diabetes.

This should not however be construed as merely a question of choice. For example, Munira says she has changed her style of cooking and has stopped baking altogether. She goes on to qualify this saying that her children are adults and therefore she no longer has “...to do the baking for the children”. Consequently, it can be seen that Munira does not feel compelled to define herself as a good mother in quite the same way as Theresa. The options available to the individual for the way they view themselves are constrained by social beliefs, such as the moral need to be a good mother to small children and the need to portray the personal attributes associated with that notion. They are also determined by social condition, such as actually being a mother of small children. While the individual may express his or her own subjectivity, this is not done in circumstances of their own choosing (Nightingale & Cromby, 2002). The person with diabetes must find place for management activities in a way that accommodates various roles to be performed while continuing to work within their own particular context.

Social interactions carry certain rules of engagement and expectations of those involved that can compel the person to behave in a particular way which might be at

odds with management activities. For example, in Indian culture, certain behaviors are expected of both the host and guest. A good host will make guests feel at ease and urge food and drink on them. The good guest must relax and enjoy the hospitality that is provided. In this way the role of a good guest is fulfilled while allowing the host to fulfill their role as well. This can potentially cause tension between the need to be a good participant in social exchanges by fulfilling the role that is socially and culturally expected, and the need to be a good patient and fulfill a role that is medically and morally expected. Mrs. Mullah is “teased” and told not to be “shy” when she eats small quantities, even though she assures her friends that she is satisfied. She must therefore find a way to hold in place her convictions regarding her diet while reassuring her social group that she is still engaged in their social practices.

Food is an important part of the way in which Indian cultural identity is expressed and, for Indian migrants, a way in which continuity is maintained with the past (Tresslor & Chamberlain, 2005). The exchange of sweets and other foodstuffs during religious festivals are a part of cultural tradition, and the Indian person with diabetes must find a way to preserve these traditions. Participants manage this by making festival fare and giving it away without partaking of it, eating only small amounts of what is put in front of them or continuing with tradition and taking remedial action later. Choosing to limit participation in activities believed to express cultural allegiance can inhibit certain relationships. The importance placed by participants on social bonds means that they may try to preserve the fundamental nature of relationships as far as possible. With the construction of diabetes as “aggressive”, certain changes are validated. Relationships or social activities believed to be disadvantageous in the attempt to manage diabetes might wane, while allies with matching goals and lifestyles are sought out. For Munira, choosing to limit her interaction with certain connections has resulted in a consequential effect on other relationships. This demonstrates that individual relationships are not discrete but rather a part of a complex network of social connections. As a result of her

I’m also with friends who think... who are not into too much of entertaining and parties and (pause) I had to remove myself from that group at the expense of upsetting some family people. But then I had to look after myself. So my lifestyle has changed. There are times when I’m forced into this because of the cultural aspects of our lifestyles. There are a lot of people coming and going and entertaining and eating and frying this and, you know, feeding everyone else. I do much less of that than I used to. I’m focusing more on spending time with a friend who likes walking rather than one who might like to have a dinner party on the weekends.

decision to alter one relationship, Munira has found that her relations with her family have been affected. The complex nature of social relationships can complicate the implementation of a change in lifestyle.

The decision of how diabetes can be managed is not only important in the cultural context. It is also an important consideration with regard to other social gatherings. Chandrashekaran says that he will eat something “extra” during the day if faced with an “office function” such as a farewell party for a colleague. People both present themselves and are critiqued by the extent to which they conform in social situations, and the need to fit in and be well thought of can make it difficult for the Indian person with diabetes to refuse certain foods or limit the amount that is consumed. This is true for social events within the cultural group as well as outside it and might be particularly important for migrants in the process of establishing themselves in new work environments and new lives.

While talking about diabetes and the impact it has on life, participants also aligned themselves with particular social or cultural groups depending on the perceived characteristics of these groups and the extent to which they see these characteristics within themselves. Participants made statements such as: “Punjabi people take sweets”; “Indian women have a habit of wanting to cook hot meals, fresh meals...”; and, “I am doing simple exercise that have been prescribed for the senior citizens”. These are not merely statements about issues being faced in the attempt to manage diabetes or about the reason why certain things are done or not done. The self is known and portrayed through drawing on social and cultural norms (Gough & McFadden, 2001). The statements made by participants are therefore also about the way they see themselves and, by making such declarations, participants are validating their position as members of particular cultural or social groups. Maintaining the connection with their cultural group can become very important for the person of Indian origin who faces difficulties such as a language barrier or limited social support. Understanding and dealing with diabetes is therefore not limited to fixing the boundaries of diabetes, understanding the effect it has on the body and working out what should and could be done to control it. It is also about examining the self in the context of diabetes and working out a way to

continue to preserve, transform or affirm these perceptions of the self in the context of diabetes self-management.

In addition to being vigilant themselves and the vigilance of the medical profession, participants also describe the vigilance of their partners and other family members who, they believe, play a "supporting role". While the person with diabetes is the main player and must assume primary responsibility for diabetes, family and friends also have their part to play. Participants describe the extent to which the family meals are adjusted to their needs. Lifestyles are often described using the pronouns "we" and

My wife and me... because I was diabetic she stopped eating all sugar because she thought I'll be tempted and then she ran up on a low sugar but now it's ok its under control. And so she also keeps reminding not to eat this not to eat that and then rather than saying she just tries to keep nothing on the table like that, in the house or in her menu and once in a while, once in two weeks or three weeks then she makes something special she comes and says this is for you. We are not kids to say I need everything so she also understands and I also... I mean who else bothers about you?

"our" even when just one partner is diabetic. For example, Mr. Duggal was asked if he had made any changes after being diagnosed with diabetes. He talks about the medications he has been prescribed using the pronouns "I" and "me". When talking about his diet, however, he says, "...except the paratha in the morning which we could not discard so far, other things we are eating normal. We take little precautions about it, so the fruit and vegetables which contain lot of glucose value, we try to avoid to some

extent." Even though Mr. Duggal's wife is not diabetic, his answer indicates that he does not separate himself from his wife when considering the aspects of every-day life that they share. Similarly, other social interactions are also based on shared needs and circumstances. So, while friends might show support by making food that is appropriate for a person with diabetes, social functions often run late into the evening making the timing of the meal problematic. In this way, many of the issues surrounding the management of diabetes are communal rather than individualistic. Thus, describing the management of diabetes as *self*-management is limiting and does not reflect the collaborative aspect of the way in which life is lived.

In addition to chronological age, the "personal life" is used to biographically locate and chart the onset and progression of the disease. Participants appear to divide their lives into events that occur because of diabetes and life-events that happen despite it. Events, such as the diagnosis of diabetes, are linked to other socially constructed

events thus integrating the two and providing continuity and coherence to the diabetic existence. For example, Theresa uses her mother's holiday in Dubai to locate her diagnosis and the birth of her own daughter to recount her diagnosis.

She had it, I think, just after my brother was born and he's about 6 years younger to me I'm 32 and my mom was on insulin she was very heavily diabetic. We didn't realise she had it until she went for a holiday to see my dad. My dad used to work in Dubai. She had lost so much weight. She would get up in the nights to go to the loo and so my dad was like you need to check your sugar and that's how they found out. Anyway, just seeing my mom go through it - she was in and out of hospitals in India because she was so bad and so heavily diabetic and she would never ever stick to a diet and of course she was... my mom passed away six years ago. She had a heart attack. Yeah that was a major shock for me because I had just had my son in Feb, I christened him in March and she died one day later. It was extremely sudden and shocking because she was extremely young, only 50 years old.

The linkage of these events also reveals Something more about the meaning these diabetic events might hold in the context within which they occur. The christening of her son is used not only to locate her mother's sickness within Theresa's life story. It is also used to give a sense of the emotion and meaning behind the loss of her mother to diabetes. A picture is therefore created of the disruption and loss that diabetes can bring about within the family of the sufferer. Similarly, looking at the quote by Mrs. Khan on page 39, she is not merely describing her struggle with diabetes and her fight to keep off insulin; she is describing it within the context of

her life and the stresses and struggles therein. In this way, diabetes is incorporated into the life-story of the person giving it meaning beyond physical experience. And it is not just that life is lived in the context of diabetes, it is that diabetes develops and is given meaning within the context of life.

Changes that occur relating to diet and activity levels are also often portrayed as being a result of changes in this "personal life" rather than as deliberate attempts to modify lifestyle. Chandrashekaran believes that his diet changed significantly when his wife began work outside the home. Mrs. Bajaj feels that, although she has been very active throughout her life, she has become more sedentary after retiring. Both these statements are made in the context of the way in which diabetes is managed, but are also statements regarding events in the life of the individual. Thus the progression of diabetes both affects and is affected by the events that occur within the life of the sufferer. In this way, not only is the disease integrated into the future life of the

person, it becomes a part of personal history. With the belief in the hereditary nature of the disease, it also becomes a part of family lore.

Participants describe using their diabetes as a warning to their children and grandchildren. The belief in a hereditary link means that they are concerned about the future health of their family members. The person with diabetes is not only engaged in understanding diabetes and working out how to deal with it, they are also engaged in passing on the knowledge and experience they gain in the process. This is a way in which the person with diabetes expresses care for family and friends. It is also a way of rallying around and supporting fellow sufferers by “helping” them to “go through the process”. The diabetic body is used to illustrate the effects of diabetes and to warn against “worst case scenarios”. “Seeing” the effects of diabetes on someone else is a source of information for the person of diabetes. It is a way in which a tangible link is created between doing the “wrong things” and possible complications of unmanaged Type 2 diabetes. In this way, the hypothetical situations proposed by doctors become visible and more concrete for the person who is suffering few ill-effects from the disease. The stories of friends and families are thus used to illustrate the effects of unmanaged diabetes. By comparing themselves with other people with diabetes, participants were able to form a picture of diabetes, its management and complications and also to assess their own condition.

This has got some bad effects like amputation of toes and mainly from the foot side and weakness, tiredness, loss of sleep and some other problems that we should not have. But it leads to problems if our diabetes is more than 12 and that is never good. When I got diabetes I started taking precautions. Less meat, less sweets less other sugary articles. It is for me only, I have to take the advantage. If I am go on taking all these things, now I am 69 plus so after another one year or two years I will be having some other problems like amputation and these things like that. Like my wife has got it, she has got two toes amputated. I don't want that (laughs)

The way in which we understand ourselves is shaped by the collective representations of the society within which we live (Crossley, 2001). These shared accounts involve basic systems whereby the body is made meaningful through classification based on certain physical markers. The social correlates of the body become recognised symbols of race, gender and age (Crossley, 2001). Being Indian does not only imply working from within a particular cultural framework, it is also means having a body that is Indian with recognisable ways in which this body is

different to other bodies. This bodily distinction serves to further highlight cultural difference. Among participants there is some feeling that there might be a normal state of being for the Indian body which is not accounted for in “English medicine”.

Chandrashekarana believes that the minority status of Indians in New Zealand limits the practical experience and understanding available to health professionals who deal with this population group. This leads to some apprehension regarding western biomedical criteria for the classification of the body as diabetic. In such situations, it may be felt that the individuals own evaluation of the state of their health would be more accurate than that of their doctors. These reservations can serve to explain discrepancies between biomedical assessment and personal perception of diabetes and allows for flexibility in the way that diabetes is managed as well as in the formulation of an acceptable picture of the disease. Lack of confidence in the medical profession leads Chandrashekarana to “check” with “Indian doctor friends” and take homeopathic medicine in addition to the medication prescribed by his GP, even though his homeopath and GP may sometimes differ in their interpretation of symptoms and test results. Others describe seeking out doctors who have similar perspectives on the way in which good health and ill health may be defined.

A preference for GP’s from the Indian subcontinent, such as Indians, Sri Lankans or Bangladeshis was also seen amongst the participants of this study. They describe being satisfied and feeling understood by these doctors even though, for some, there are language differences and some difficulty in communication. This suggests that the understanding referred to is not merely lingual, but of body, history and space which is shared more closely with doctors from the Indian subcontinent than with their European or North Asian counterparts.

The social environment is therefore both the situation in which the diabetic body is enacted as well as a source of information, support and constraint. Through the enactment of the body certain ways of being are characterised and particular social worlds are constructed (Radley, 1998). This, in turn, legitimises or makes unacceptable the activities related to the management of diabetes. The biomedical account of the diabetic body and the person’s own experiences of the diabetic body are made sense of within a particular belief system that is influenced by Indian culture as well as the social

position of the individual. Meaning-making in diabetes also involves locating it coherently in the biographical narrative in a way that the physical characteristics of the disease, the behaviors required to manage it and perceptions of the self make sense within the belief system of the person with diabetes. The decision on how and when to act to manage diabetes is also affected by the theory that is held of the self and the position that is chosen for embodied action. Preferred positions on the management of diabetes are taken up within a social and cultural framework; some options regarding position can be limited and dependent on circumstance.

The whole package

In bio-medicine, diabetes is a chronic metabolic disorder. As a result, there are certain changes within the body that can be monitored by removing blood from the body and examining it. The disease is understood in terms of chemical reactions, risk factors, complications, and therapeutic recommendations. However, the person with diabetes does not view diabetes with this same objective scrutiny but engages with the disease practically. To the person with diabetes, making sense of the disease involves a complex set of, social, physical, functional, medical and introspective evaluations. This discussion, the diabetes literature and participants themselves use the term “lifestyle change” to describe the changes that are recommended as part of the attempt to control diabetes. As Rohan, a participant in this study, emphasised, lifestyle refers to the “way in which we live our lives”. Thus the management of diabetes does not merely involve an action that is independent of all the other activities that the individual is engaged in. It involves trying to fit management activities around “the other stuff that’s happening” as part of the way in which the person with diabetes lives. Therefore incorporating the therapeutic recommendations for exercise and dietary change must be accomplished while taking into account work and family commitments and personal feelings, such as being tired after a long day at work. Even the action of taking medication requires that the person with diabetes remembers to take the tablet at the correct time. He or she also assumes the responsibility for fine-tuning the dosage based on their assessment of whether dietary and exercise requirements have been met for that day.

Bury (1982) argues that chronic illness causes a disruption in the structure of everyday life and an increase in uncertainty with regards to the future. The individual is forced to confront the reality of suffering and death that might otherwise be visualised abstractly and to find meaning in the development of their condition. Bury (1982) therefore considers chronic illness to have a disruptive effect on the biography of the individual. While these impressions were also gained from participants in this study, it is also apparent that participants work to overcome this disruption to facilitate the incorporation of diabetes into their life-stories.

In order to meet the challenge of incorporating diabetes into the way in which life is lived, the person with diabetes must draw the fragmented body together to create a coherent picture that includes diabetes, any co-morbid health problems and their respective management activities. Although the interview questions focused on Type 2 diabetes, participants included all co-morbid issues in their responses. Participants were able to differentiate between the management requirements for their various conditions, and combining the various conditions and management plans should not imply a lack of awareness. The joining together of different health problems suggests that the body is viewed as a whole. However, as Mol and Law (2004) explain, it is not a consistent whole but rather a set of tensions arising out of a complex interplay of circumstance and belief.

The location of diabetes within the body does not merely imply a subject who is trapped within this body and who must then adapt to the limitations that this produces (Williams, 1999). The participants of this study are actively engaged in understanding and composing the diabetic body through drawing on social, including bio-medical, notions. However, as McHoul and Rapley (2005) argue, the understanding that is referred to here is not merely representational. Rather, to understand diabetes and the diabetic body is to become competent at *doing* them in a manner that is coherent in a variety of contexts and so as to achieve some purpose. To the participants in this study, the linguistic representation of the body does not happen in isolation from corporeal experience or social practice. While the person might choose to constitute diabetes through linking certain bodily sensations together, it is through engaging with these

sensations, in a manner that makes sense socially and culturally, that the disease and the diabetic body is comprehended.

Through the understanding and enactment of the diabetic body, the self is also renegotiated, reconstructed or held in place to accommodate the difference and impairment that the disease is believed to engender. This is done through drawing on, navigating around and holding in place social and cultural notions that the people have of themselves and the roles that they play. Although these notions play an important part in the way in which the person might react to diabetes, people with diabetes, such as Theresa, who struggle with a perceived conflict in roles, should not be considered passive victims of tradition. They are sentient, clearly aware and able to articulate the various aspects of their position, the options available to them and the obstacles they perceive as barriers to adopting certain management activities. Social and cultural beliefs are not the only dynamics that shape the way in which the self is reconstructed to account for changes brought about by diabetes. Because we are embodied beings with bodies that, though discursively presented, have a material form, there are certain “fleshy” (p. 811) limitations on the degree to which the concepts of the self can be reconstructed (Williams, 1999). So, the way in which the body is understood and managed is influenced by the way in which the self is visualised and the way in which the self is renegotiated in the context of Type 2 diabetes is limited by the diabetic body.

Understanding and dealing with diabetes therefore requires that the person with diabetes negotiate issues around the characteristics of the disease, the limitations of the body, a variety of management activities, various sources of advice and support and considerations of self, family and society. In this way, diabetes requires the scrutiny and re-assessment of the body, the taken-for-granted activities of daily life, familial and social relationships and the way in which the self is constructed and portrayed. The understanding of diabetes that emerges is unique to the particular situation faced by the person and the particular life-style they aspire to.

Concluding comments

The aim of this study was to explore the way in which people of Indian origin with Type 2 diabetes understand the disease and position it within their daily lives. To accomplish this, it was considered necessary to gain an insight into the way in which diabetes is given meaning within the socio-cultural context of being Indian in New Zealand, rather than merely setting out to catalog cultural ‘representations’ of diabetes. While these might have been valuable in themselves, it is felt that a richer understanding is achieved because the findings of this study represent the work that is done by the person suffering from diabetes, to not only understand and explain diabetes, but also to enact it.

What has therefore emerged from this study is a complex picture of the way in which explanations of diabetes are constructed, the personal and cultural histories that lie behind them, and the obstacles and assets involved in incorporating diabetes into everyday life. Most of all, the study never lost sight of the *person* with diabetes. This is an acknowledgment that diabetes cannot be removed from the embodied being and studied dispassionately; rather it is the way in which the situated person engages with the disease that is believed to be of significance. Reflecting on the cultural context of being Indian and the social context of being Indian in New Zealand allowed me to draw on my own experiences as an Indian migrant. Reflecting on these while listening to the stories told by the participants of this study brought into focus the taken-for-granted beliefs and history that shape the sense of being Indian; making me more aware of being Indian in the process than I have ever been before!

Although the intent of this study was never to produce a generalisable result, it is acknowledged that the views of certain people of Indian origin who, being in the

minority and therefore of diminished visibility, might not be represented. Participants selected for the study were all capable of communicating in English and were able to make contact with GPs who, they felt, understood them even if language was an issue. The constraints and strengths of language, and the challenge of communicating with others in the absence of a common language, have therefore not been adequately explored in this study. The participants selected represent the main urban areas of India and reside in Auckland, a major urban centre in New Zealand. Given that the participants showed a preference for GPs from the Indian subcontinent, how do other people of Indian origin deal with the possibility of not having such a choice? How would they deal with such a limitation if also confronted by language issues?

To some extent, this study and others like it, reinforce the medical view of diabetes as problematic, and of those who do not adequately control it as in need of 'intervention'. Chandrasekaran, a participant in this study, challenged this idea, proposing that what might be considered the markers of diabetes might simply be markers of a different way of being. However, as was seen in this study, there are physical phenomena experienced by some people and, whether or not these are regarded as symptoms of diabetes, to disregard or minimise them and the concern they engender would be to disadvantage and marginalise the person. The label 'Type 2 diabetes' might therefore be considered a convenient means within which to enclose the beliefs and fears that are held by the people in this study, rather than the furthering of medical discourse. It is also acknowledged that what might emerge is a way of increasing surveillance and institutional control over this community (Salmon & Hall, 2003).

In dealing daily with their illness, the people with diabetes in this study made sense of and resolved the challenges they face within the context of their socio-cultural understandings and within the physical limitations of the disease. Explanations for the diabetic body and diabetes in the narratives of participants can be traced back to cultural notions regarding illness and the way in which ill health can be treated. In addition, there are strong moral ideas regarding health and healthy practice that underpin understandings of responsibility for the development of diabetes and for its management.

Beliefs about self, life and the lives of others influence the way in which we deal with the phenomena of life (Benson, 2001). According to Karas Montez and Karner (2005), chronic illnesses, such as diabetes, require a reframing of the body and the self, and this can jeopardise established ways in which the self and everyday life are perceived and enacted. This study showed that the person with diabetes is engaged in resolving the tension between familiar, pre-diabetes notions of their bodies, of themselves and the roles they play within their social systems, and the new circumstances that arise out of having diabetes. They are expected to take up the role of a good diabetes patient and this involves creating a coherent idea of what this might be and where this fits in with their own understandings of what is required of them socially and culturally.

Through their embodied narratives, people are constantly constituting their sense of self (Crossley, 2000). The manner in which the people in this study talked about their illness and the way in which they deal with it, reveals a picture of the sense they have about themselves, their qualities, attributes, strengths and weaknesses. In relation to the management of diabetes, the construction of the self involves assumptions about a social and psychological reality and the taking up of a preferred subject position. This either allows for or inhibits the possibility of different constructions of the self. For example, depending on understandings of being a mother, being a guest, being a family member or being employed, and understandings of being a person with diabetes, taking up more than one position may or may not be possible. The self, as understood by the individual, plays an important part in the way the individual navigates the lived experience through the creation of symbolic worlds that are grounded in the physical world as perceived and understood by the individual (Benson, 2001).

Connor and Norman (1998) feel that the way in which the self is conceived can be a predictor of behavior. This study finds that, with the way in which the self is constructed, certain behaviors become justified and sensible while others are perceived as problematic. Talking and thinking about the self creates a reality of the self that opens up or limits opportunities for action (Benson, 2001). The people with diabetes in this study define themselves by assigning certain characteristics to themselves, such as a lover of food, and align themselves with social groups, such as senior citizens or

Punjabis. They define the roles that they play, such as being a good mother or being a good patient. These various constructions of the self enable or inhibit certain behaviors which might impact on the way in which Type 2 diabetes is managed.

In order to be more effective and appropriate, diabetes management programmes must therefore address the notions of self that underpin the decisions that people make regarding their diabetes. Other studies have pointed out the importance of culturally appropriate education in connection with empowering people of South Asian origin to better manage their diabetes (for example, Stone, Pound, Pancholi, Farooqi & Khunti, 2005; Chowdhury et al. 2000). The people with diabetes in this study demonstrate that they are already cognisant with therapeutic information and are engaged in negotiating an understanding of diabetes that fits in with their cultural values and understandings. This suggests that education is not the only answer to increasing the effectiveness of management programmes and instilling a sense of empowerment in people with diabetes. The findings of this study suggest that, in order to fully realise an empowerment approach to diabetes management, it is necessary to help the person with diabetes reinvent the self in a positive manner that is in line with cultural and social needs, and still allows for the implementation of management activities and lifestyle change. The people in this study define themselves by what they do and will not do. Part of the way in which diabetes is handled in the health system therefore needs to be the provision of help for people who are inadequately managing diabetes, so that they may continue to define themselves in an appropriate way, while allowing for better management of diabetes. As McKenzie (1997) says, health is not something that can be given; it is created in a dynamic process that allows for different stories to be heard, while facilitating the construction of alternate stories and of a new history. In this way, subjection might be resisted allowing the person to regain a sense of agency (Drewery & Winslade, 1997).

There is some common ground between the explanations of diabetes and therapeutic objectives promulgated by the health system, and the understandings and goals of the people of Indian origin of this study. Health professionals are viewed positively and depended upon as a reliable source of expert knowledge and advice. However, explanations from other medical traditions are also drawn on, as are cultural

notions, personal experiences and information from non-professionals. The people in this study thus revealed that they are not submissive consumers of bio-medicine or of any other conventions. Rather, practices are considered, assessed, justified and adopted in such a way that everyday life continues in a coherent manner.

The status ascribed to health professionals implies that they appear to be an appropriate starting point for management interventions with this ethnic group. There are, however, some issues that need to be addressed in order to realise the objective of culturally appropriate care advocated by the Health Strategy of the Ministry of Health (2003a). The concern regarding whether the Indian person is adequately understood - linguistically, culturally and physically - is one such issue. The identification of the contemporary form of medicine practiced in New Zealand as a western development is associated with the apprehension that the medical system is not geared to deal with the Indian physiology.

This is reinforced to some extent by the way in which the management and prevention of Type 2 diabetes is approached in New Zealand. Maori and Pacific Island groups are often held up in comparison with the European population in New Zealand; for example, the DHB Toolkit for diabetes produced by the Ministry of Health (2003a) and the Evidence-based Best Practice Guideline produced by the New Zealand Guidelines Group (2003) for the management of Type 2 diabetes contain specific references to these groups or have sections that focus exclusively on them. This makes these groups prominent and implies that there is little information or interest in other sub-populations, who are often amalgamated in statistical information under the category “other” or “Asian”. The search for information that was performed as a part of laying the ground for this study reveals that there is very little culture- or ethnic-specific information available on diabetes in New Zealand. While studies, such as this one, will go a long way towards gaining a better understanding of the social and cultural basis for the way in which diabetes is understood and dealt with in everyday life, there is also a need for greater visibility of minority ethnic groups within the New Zealand health system.

The study also revealed that there are certain people who, through their understanding of diabetes or the choices that are available to them, might be more

vulnerable than others. There are some people with diabetes, such as Theresa, who are slipping through the cracks of the current system in relation to dealing with their diabetes. It is not that they are denied access to the resources available to other people with diabetes; it is that these resources do not adequately address the issues that they perceive to be barriers to the effective management of diabetes. People who consider diabetes to be an inevitable part of the ageing process and therefore accept it as a part of life, rationalizing minimal efforts at management, might also be unnecessarily exposed to an increased risk of complications. Clark and Asimakopoulou (2005) caution that the attribution of physical and intellectual deterioration to the ageing process rather than as symptoms of diabetes can result in a failure to diagnose the disease or to adequately manage it. This study also highlights the importance of increased screening for high risk groups. Many participants in this study were diagnosed by chance. Although diabetes might be apparent within the family, the prospect of developing it is not easily recognised. There is therefore a need to understand the way in which people without diabetes perceive the risk of developing the disease, with a view to arresting the meteoric rise in the number of new cases that are diagnosed each year.

Regarding the way in which diabetes is managed, two findings from this study are considered worth highlighting. Firstly, every activity carried out during the day can be considered part of the management process for diabetes. This is because the therapeutic regimens recommended by the health profession must be shaped to fit in with all the other activities that are performed as part of everyday life, which, in turn, must be restructured to accommodate the strictures of a diabetic existence. The participants of this study felt that self-control and the acceptance of responsibility were an important part of managing diabetes. However, assuming responsibility and possessing the intent to make changes in lifestyle does not imply the *capability* to carry out these changes. There are social and physical limitations that can systematically disempower the Indian person with diabetes, and these must be taken into account when considering the way in which diabetes is managed. Thus, when attempting to help people improve the way in which they manage the disease, the scope of interventions must be broadened to include the whole picture of the way in which life is lived. Secondly, everyday life is lived collaboratively and decisions regarding lifestyle are

based on shared needs and benefits. Because everyday life is collaborative, lifestyle change also becomes collaborative and negotiated rather than self-determined. Thus the term “self-management” is limiting, and it is suggested that the management of diabetes be viewed as a cooperative venture. This should not be interpreted as a suggestion that decision-making power does not lie with or should be removed from the person with diabetes to be located with a corporate entity. Rather, it is the belief that the Indian person with diabetes will not be able to implement certain changes in lifestyle without the support of family and community.

Salmon and Hall (2003) argue that discourses that construct the patient as agent in the management of disease may serve bio-medicine rather than empowering the patient. Such discourses remove the responsibility for challenging and problematic aspects of medical care, such as chronic disease, from the medical profession and locate it with the patient. They can also *restrict* control by failing to recognise the patient’s personal concerns regarding their disease in favour of therapeutic concerns or by inhibiting the possibility of turning to the medical profession for assistance because of the way they are framed (Salmon & Hall, 2003). The formulation of management plans, and indeed any future research on any form of lifestyle change, should therefore consider the negotiated and shared aspects of life. It is also recommended that people with diabetes be provided with the resources with which to seek and gain the support of those who are intimately involved with their lives, including the health professional. In this way, it might be possible to move from a limiting, and perhaps disempowering view of the *self*-management of diabetes to a liberating and empowering view of the *sustained*-management of diabetes.

Understanding and dealing with diabetes, finding a place for it in the life-story and finding a way to continue living life is a complicated, turbulent process. It is inextricably intertwined with issues around society, the medical profession, co-morbidity and personal inclinations. Regardless of whether the person with diabetes chooses to implement the management activities recommended by health professionals, there are changes that are forced in every aspect of their life with the advent of diabetes. Furthermore, whether the person believes a change in behavior is warranted or not, certain physical manifestations of the disease are experienced, thought about and

agonised about. The management of diabetes for people of Indian origin is not just the management of diabetes, but rather the management and re-creation of the whole person.

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