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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 choose 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 lead 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-Statin, Cradock & 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 lead 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 *honesweet* (Diabetes
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 Downs 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 dieticians 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 collectivist 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) describes 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 Tressler 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

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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.