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**NARRATIVES OF LIVING WITH DIABETES:
AN EXAMINATION OF SELF, IDENTITY, AND THE BODY**

by

Joanne Goldman

**A thesis submitted in conformity with the requirements
for the degree of M.Sc.
Graduate Department of Nutritional Sciences
University of Toronto**

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**Master of Science, 1997
Joanne Goldman
Graduate Department of Nutritional Sciences
University of Toronto**

ABSTRACT

This study examined the personal and social meanings of living with insulin-dependent diabetes mellitus through an integration of social theory with individuals' everyday experiences with diabetes. The theory of narrative, identity, self, and the body, was used to illuminate the continuous processes involved in being an individual with diabetes and to contextualize the challenges to managing diabetes. Transcripts of unstructured interviews previously conducted with four women who have diabetes were the basis for this study. Diabetes narratives were used to construct identities and selves and to interpret one's bodily experiences. The self as a cognitive, reflexive, subjective, and physical experience, identity as a temporal and relational construct influenced by others and one's own recognitions, and the body as a lived experience and as a product of cultural themes, provided the framework for a deeper understanding of the personal and social context in which the meaning of diabetes was constructed.

ACKNOWLEDGMENTS

I would like to express a sincere thank-you and appreciation to the individuals who have provided me with the support and guidance which was instrumental to the development and completion of my thesis.

I am deeply grateful for having had the opportunity to work with my supervisor, Heather Maclean. Her valuable insights and guidance, her confidence in my abilities to pursue alternate ways of thinking, and her continuous support, enabled me to grapple with challenging ideas and to have an enriching educational experience.

I am extremely appreciative to the members of my thesis committee, Valerie Tarasuk and Victor Marshall for their contributions to my thesis. Their particular expert backgrounds were instrumental in shaping both my thesis and my way of thinking. They guided me through essential areas of knowledge and encouraged me to think critically.

A final thank-you is to my family for their constant support and encouragement to pursue my educational goals.

I would like to acknowledge the financial support I received from the Ministry of Education and Training during this research project.

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1. INTRODUCTION

From a biomedical perspective, insulin dependent diabetes mellitus (IDDM) is a chronic metabolic disorder characterized by an insufficient production of insulin by the pancreas which leads to elevated blood glucose levels. The medical treatment of IDDM involves injections of exogenous insulin, diet management, and exercise, with the goal of controlling blood glucose levels (see Appendix A for a biomedical discussion of IDDM). Diabetes management is a constant, daily necessity for both immediate and long term health. It has been demonstrated that intensive management of IDDM can delay the onset and slow the progression of long term complications including diabetic retinopathy, nephropathy, and neuropathy (The Diabetes Control and Complications Trial Research Group, 1993).

The biomedical perspective of diabetes is one important aspect of the meaning of diabetes. However, a chronic condition such as diabetes has many layers of meaning to individuals who live with it and thus can be explored through various theoretical perspectives. Individuals who have diabetes make sense of the condition within the social and cultural contexts of their lives. The significance of having a chronic condition, the influence of diabetes on relationships, the demands of behavioural changes, the implications for one's social and economic roles, and the threat of long term complications, are only some of the issues which these individuals confront.

The social and cultural processes which shape the experience of diabetes are complex and overwhelming. It is important to understand the role that these forces play at the individual experiential level and also how these forces influence the construction of the experience of diabetes. One way of contextualizing these forces is through an analysis of the

interaction between diabetes and individuals' selves, identities, and bodies. This focus allows for an exploration into the personal and social aspects of chronic illness and individuals, as well as a recognition of the integral aspect of embodiment.

The sociological literature on chronic illness and identity has illuminated the importance of recognizing the personal meaning of living with an illness on a daily basis. Some of the previous literature in this area has used a symbolic interactionist perspective of identity and the self and has focused on categorizing identity levels or changes, and on the disruptions and reconstructions of self and identity (Charmaz, 1987, 1995; Mathieson and Stam, 1995; Yoshida 1993). Recent theory about identity and self has built upon the symbolic interactionist perspective and has added new ideas that will be used in the current study to further understand the experience of chronic illness beyond previous approaches (Calhoun, 1995; Frank, 1995; Gubrium and Holstein, 1995; Somers, 1994).

A significant focus that has recently been emerging is the link between identity and narrative. This theory will be explored in this study within the context of diabetes. Narrative has been described as a process of understanding the way that people experience the world through the stories that they tell (Connelly and Clandinin, 1990). In daily life, individuals tell stories in order to give coherence and direction to their lives and as a means of developing their identities (Polkinghorne, 1988). Frank's (1995) work demonstrates the value that he attaches to an exploration of narrative and the self within the context of chronic illness. He suggested that "illness is an experience, a reflection on body, self, and the destination that life's map leads to" (p. 7). He said that medical narratives of illness dominate the modern period, and it is necessary in postmodern times for individuals to tell their own experiences of

illness through the stories which permit them to “reclaim” their illness and to repair the “narrative wreck” that illness causes. As Frank said, we have the responsibility to “witness” individuals’ testimonies.

Frank (1995) discussed the significance of the body which is another developing area in the context of chronic illness. According to Turner (1992), the traditional mind/body dichotomy and the neglect of human embodiment are theoretical and practical problems in the social sciences. The study of chronic illness, self and identity, seems to be an exploration which necessitates the inclusion of the body. Turner’s claim that an appreciation of the body allows for an understanding of the experience of illness as not merely being an attack on one’s instrumental body, but as an extreme incursion into one’s embodied selfhood will be analyzed in this study in the context of diabetes.

The goal of this thesis is to explore how narratives are used to construct selves and identities and to interpret one’s body during the experience of insulin dependent diabetes mellitus, which will be referred to as diabetes throughout this thesis. The focus will be on the construction and content of the stories told and on the process of storytelling, and how these relate to self and identity construction and to embodiment. A qualitative narrative analysis will provide insight into why storytelling, and the notions of self, identity, and the body are critical to understanding the experience of living with diabetes.

2. LITERATURE REVIEW

2.1 Chronic Illness and identity

The literature in the area of chronic illness and identity has provided insights into the experience of living with a chronic illness. The notions of losses and disruptions, the personal and social meanings of illness, the concepts of time and control, and others' reactions, are all significant issues which have increased our understanding of the challenges to living with a chronic illness. The ideas suggested in the literature are valuable, yet there is a need for further exploration and conceptualization of the complex processes involved in the construction of self and identity in the experience of chronic illness.

The personal and social meanings of illness in general, and of one's particular illness, shape how identity and self are affected during the experiences of chronic illness (Charmaz, 1987). A significant focus in the literature has been on the disruptions and losses which occur to the self resulting from the demands and effects of chronic illness, and the process of reconstructing one's self and identity. As Corbin and Strauss (1987) claimed, chronic illness separates the person of the present from the person of the past, and influences images of self envisioned for the future. The meaning and extent of the felt losses will depend on the perceived value of these attributes and actions to the self. Others' reactions play a significant role in this interpretation process.

Packard, Haberman, Fugate Woods, and Yates (1991) studied the experiences of women who had nonmetastatic breast cancer, diabetes, and fibrocystic breast disease. They categorized certain experiences as "personal disruptions" which involved disruptions in a sense of personal continuity and personal integrity. Within these classifications were feelings

of uncertainty, unmet personal expectations, future concerns about self and others, direct confrontation with time, and troublesome alterations in one's sense of being a whole or complete individual. Packard et al. used the category "environmental transaction demands" to describe disruptions to interpersonal roles and relationships.

The meanings associated with disruptions and losses seem to be related to individuals' need for control. The emphasis on control in chronic illness often reflects cultural knowledge about control in relation to time and the body, such as expectations of body function and relations to clock time. Individuals strive to achieve a balance between controlling the illness and being controlled by the illness (Charmaz, 1991). Charmaz suggested that individuals' struggle for control represents efforts to control the defining images of self. This struggle is manifested in experiences of managing daily life, dealing with illness, and making sense of it.

Roth (1963) studied the experience of tuberculosis and developed the concept of timetables to explain how patients and doctors defined the career of tuberculosis in terms of time. Charmaz (1991) further elaborated on the concept of time as a significant factor in contextualizing the meaning of illness and the resulting implications for identity. She suggested that illness preempts self images along three time dimensions: the daily round, the life structure and the life cycle. Illness demands a refocusing of one's time perspective which leads to changes in self concept. This central role of time is demonstrated by the effects of illness on daily activities, time required to manage illness, the influence of illness on future plans, the expectations of self at different stages of the lifespan, the role of time markers in explaining one's illness, and significant turning points in one's illness experience.

The definition of the illness and the resulting implications for identity are influenced by

one's own interpretations and by the evaluations of others. Family, friends, health practitioners, co-workers, etc. all play a role in defining the individual's illness. Individuals' desired identities are negotiated with and evaluated by others. Others could block or support one's desired identity, and conflicts over identity definitions and types could cause problems (Charmaz, 1987). Goffman (1963) distinguished between social identity, personal identity, and ego identity. Social identity consists of the categories and attributes that are assigned to an individual through the routines of social interactions. Personal identity defines an individual's uniqueness; it consists of an individual's identity pegs, a concept developed by Goffman to describe such characteristics as the photographic image of the individual or her/his fingerprint, and the individual's particular combination of life history events. Ego identity is the subjective and reflexive experience an individual has of his/her own situation which is shaped by social experiences. Goffman explained that each type of identity is concerned with different aspects of the experience of stigma and interactions with others. Another theoretical analysis that could be used to discuss the tensions of identity is Hughes' (1945) notion of master status. A master status is a determining characteristic which tends to dominate other characteristics which might oppose it. Status contradiction/ dilemma occurs when an individual has two master statuses and struggles with which one to recognize. For example, the master status of diabetes could conflict with the master status of the teenager, with resulting tensions.

It is suggested that in order to deal with disruptions and losses, a person needs to reconstruct the meaning of his/her life to position and understand the illness in terms of one's self and one's life (Fife, 1994). Corbin and Strauss (1987) used the term biographical

accommodation to describe the process of incorporating illness into life stories with the goal of achieving a sense of continuity, meaning, and control over one's life.

Researchers have categorized the processes, relationships, and interactions between identity and chronic illness in various ways. Yoshida (1993) described the work done on the reconstruction of self in the illness experience as involving either process or outcome frameworks. The process work involves how individuals achieve or attempt to achieve a sense of order of their past within the context of the illness. The outcome work involves issues such as losses of self and the struggle to attain preferred identities. Although Yoshida made this distinction, it is difficult to clearly differentiate these separate stages.

Yoshida (1993) attempted to demonstrate both the process and outcome elements in her study. She used the metaphor of a pendulum to conceptualize the reconstruction of self and identity among adults with traumatic spinal cord injury. This metaphor reflected the movement back and forth between the nondisabled and disabled aspects of the total self, which were influenced by loss, sustainment, integration, continuity, and development. The five predominant identity views were the former self, the supernormal identity, the disabled identity as total self, the disabled identity as an aspect of the total self, and the middle self. Yoshida suggested that identity reconstruction is a continuous, evolving, dual-directional process. As Geertz (1983) said, the use of symbols is a valuable means of understanding social life, and as he claimed, analogies are increasingly coming from the domain of cultural performance such as the drama or text analogy. Thus, while metaphors are a useful means of exploring meaning, Yoshida's metaphor of the pendulum might be too confining a model to capture the continuous and complex character of identity development because of its

movement back and forth within a defined space versus a forward, open approach.

Charmaz (1987) defined preferred identities as implicit or explicit objectives for personal and/or social identity that people with a chronic illness strive to achieve; fulfilling these goals overcomes identifications based on the illness. The development of a preferred identity and identity goals is geared toward leading a conventional life, avoiding dependence, minimizing stigma, and creating or maintaining a valued identity. Charmaz used the concept identity hierarchy to describe the process whereby individuals chose different types of preferred identities. Charmaz categorized these identities in descending order according to her interpretation of how difficult they are to achieve and the extent of activity demanded. She labelled the various levels as the supernormal identity, the restored self, the contingent personal identity, and the salvaged self. Charmaz's work included individuals with diabetes, but was largely concerned with other conditions which are physically challenging in a different way, such as multiple sclerosis. The term hierarchy might not be suitable for individuals with diabetes because the physical implications of the condition differ from other diseases. The term hierarchy might be problematic in general because of the categorical rigidity which is implied.

In her book, Charmaz (1991) described three ways by which individuals respond to an illness; embracing illness, incorporating illness, and containing illness. Embracing illness involves individuals' taking their images of self from the illness; the illness lends meaning to one's life. Incorporating illness involves individuals' recognizing the illness and living with it, it becomes a part of one's self. Containing illness involves keeping the illness hidden, at least in public, if not also from one's self, which might arise out of fears of loss and rejection due to

the stigma of the illness. Goffman's description of role distance is another way of conceptualizing an individual's relationship to a role. Role distance is an example of how individuals use their bodies in performances to convey how they wish to be recognized by others. Role distance occurs when an individual conveys a contemptuous detachment from the role she/he is performing in order to create a separateness between the individual and his/her role. Thus a gap is created between doing and being (Goffman, 1973). Charmaz emphasized that individuals' preferred identities and responses to illness change over time as the meanings and experiences of illness change.

Petrunik and Shearing (1988) provided a different approach in their conceptualization of the subjective experience involved in the experience of stuttering as an interaction between an "I", a "Me", and an "It", which builds upon Mead's conceptualization of the "I" and the "Me". This conceptualization introduces the subjective and objective aspects of an individual and the conflicts which could occur within an individual because of the different aspects of the self. The "I" is a source of action, the subjective aspect which is responsible for the spontaneous actions of the individual. The "Me" is the product of the inferred attitudes of other people, the objective identity that is reflected upon. The "It" is a source of action, but is experienced as a foreign force that struggles with the "I"; it becomes a central, if undesirable, part of one's identity. In the experience of stuttering, the "It" represents the foreign force which overcomes the "I" and results in an individual's loss of control over speech. The "I" strives to overpower the "It", but often the "It" is not predictable and avoiding the "It" is difficult. This conceptualization can be applied to other chronic illnesses where losses of control are significant and chronic. The cultural context and existing interpretive frameworks

will influence the way that the foreign force “It” is conceived. The “It” in diabetes could refer to the forces which challenge control of blood sugar. When individuals cannot control their bodies, the body might be seen as a foreign other, that is in conflict with the “I”.

There are various ways of conceptualizing issues of self and identity in relation to chronic illness. While this literature is valuable in explicating certain themes, an application of recent theory of identity and narrative offers an opportunity to build upon previous thoughts by providing a more dynamic, fluid, and comprehensive understanding of the significance of and connection between narrative, self, and identity in the experience of chronic illness.

2.2 Chronic illness and stigma

Goffman’s (1963) notion of stigma is an important piece of a discussion on chronic illness and identity. Goffman defined stigma as an attribute that is “deeply discrediting, but it should be seen that a language of relationships, not attributes, is really needed” (p. 3). The notion of stigma, whose meaning is shaped by cultural beliefs and social processes, influences the meanings of illness, and an individual’s daily living with an illness. Goffman differentiated between the discredited, whose differentness is known about already or is evident, and the discreditable, whose differentness is not known nor immediately perceivable. The discreditable, which could include people with diabetes, are concerned with managing information about their illness. Passing involves avoiding sharing the attribute of self, and necessitates constant attention to aspects of the social world to which others do not regularly give attention. Passing may protect one’s self from others’ reactions, but not from one’s own concerns of identity. In the case of diabetes, one’s identity as defined by social interaction,

may not be changed, but one's sense of self will be connected with the routines of managing the diabetes. The challenge with an unnoticeable stigma, is that individuals might not receive the understanding or credibility they deserve because bodily symptoms are not observable (Williams, 1988).

Disclosing information is an issue of control of information and identity, and the process of telling never ends. Disclosing involves having others judge one's behaviour, the risk of losing status or self esteem, and facing issues of stigma (Charmaz, 1991). Individuals with diabetes might risk having others judge what they eat, undermining their ability to perform certain activities, or seeing them as only 'diabetic'. On the other hand, voluntarily choosing to disclose, thus moving from a discreditable to a discredited person, might represent personal progression; individuals might no longer feel a need to conceal the illness, it might no longer be perceived as a stigma to them (Goffman, 1963). Stigmatization may vary over time and between individuals with a similar condition; the age of onset, the family's reactions, and social resources are only a few of the influences which affect perceived stigma. Thus the emphasis might be on how individuals perceive, experience, and manage the stigma potential over time and in different contexts (Conrad, 1987).

2.3 Chronic illness, identity, and the body

The meaning of the body in the construction of identity and in the experience of chronic illness is increasingly being recognized as an essential area of exploration. The term embodiment has been increasingly used, and Saltonstall's (1993) statement that the body must be understood as a concrete lived experience of socially and historically located men and

women is a helpful explanation for understanding this term. The literature in health and illness discusses the tremendous biological and social meaning which is invested in the body at both the personal and social levels of self and identity. A review of the existing literature will demonstrate what areas have been explored, and will illuminate why further study is necessary.

It is valuable to explore research on the meaning of the body within various contexts of health and illness to begin to identify the complex processes involved. Saltonstall (1993) studied the interplay between health, self, body, and gender through interviews conducted with healthy young adults. She found that the individuals described the actuality of being bodied in their concepts of health; the body and self were described as reflexive aspects of one wholeness. Olesen, Schatzman, Drees, Hatton, and Chico (1990) found that people constructed health biographies reflecting experiences of mundane ailments related to childhood events, family life, or relations with others. They learned that a concept of the physical self, as one self which existed among many selves, was grounded in individuals' self assessments of body experiences. Olesen et al. claimed that the physical self is a product of societal and cultural themes, which include available symbolic resources and expectations of everyday physical activity. The significance of the body to feelings of wholeness, the meaning of the physical body, and the influence of social and cultural forces on the physical self, are some of the important themes which might be invested with different meanings in the experience of chronic illness.

Chronic illness influences these previous assumptions about the relation between body and self. Kelly and Field (1996) suggested that when demands of the body conflict with

desired self presentation, the individual becomes conscious of the separation between body and self, and the meaning of altered bodies. In chronic illness, the body is central both to the self, in terms of the experience and feelings associated with illness, and to one's identity, which involves the social processes of managing the illness. The relation between self and identity in chronic illness is a social process which alters through time, as the bodily contingencies change. Self, identity, and body not only change but also have an enduring quality, thus there is tension between continuity and change (Kelly and Field).

Kelly and Field (1996) discussed the significance of the body. The body is the point at which the self is in touch with itself, it is the point of immediate importance for the self. The body is also a point of reference for external labels, it is a focus for the assignment of public identities. Biological facts become social facts when others respond to one's physical changes and also as individuals balance their subjective feelings with physical demands of the body (Charmaz, 1995).

The meanings of loss in relation to the body are embedded in assumptions and discourses of the body located in the larger cultural structures. Control of the body from both functional and appearance perspectives is an example of the internalization of cultural expectations of the body. Being recognized as competent social performers involves demonstrating control, use and presentation of our bodies. Control of the body provides a sense of constancy of the embodied self and the ability to plan and predict future actions (Kelly and Field, 1996).

Some researchers have developed theories about how individuals with chronic illness respond to the disruptions to self and body. Charmaz (1991) described a continuum with loss

of self at one end and transcendence of self at the other end. Loss of self refers to losing attributes and feelings that constituted one's self concept and the actions and experiences that contributed to these. Transcendence of self involves discovering that the self is more than its body and an illness, and involves reevaluation and renewal. Charmaz suggested that individuals experiencing the effects of illness can usually be located at a point between the ends of this continuum. This linear model might preclude a multidimensional understanding of the body's different levels of interpretation.

Frank (1995) suggested that being a body always requires solving problems of embodiment in order to act, but illness demands more awareness of the need to deal with these problems because during illness individuals have difficulties continuing to be the same bodies they have been. Frank proposed four general body problems, each represented as a continuum of possible responses, which must be solved in order for the body-self to act. These general problems of embodiment are control, body-relatedness, other-relatedness, and desire. Control involves the predictability of the body versus contingency, that is being susceptible to lack of control due to uncontrollable forces. Body-relatedness involves being associated with one's body versus being in a state of dissociation. Other-relatedness involves a dyadic or a monadic existence, an individual's relationship to other people. The continuum of desire refers to a person who lacks desire on one end and a body which is productive of desire on the other end. Frank suggested that frameworks such as his help delineate the body's role in individuals' stories.

Corbin and Strauss (1987) combined the concepts of self, time, and body in their development of the concept of biography. They used the term biographical body conceptions

to describe “conceptions of self (identity), arising directly or indirectly through body, as they evolve over the course of biographical time” (p. 253). They suggested that body failure and the resulting performance failure affects biographical body conceptions, and biographical work must be done to reconstruct the sense of self. The four types of biographical work are: contextualizing, coming to terms, identity reconstitution, and biographical recasting. These ideas recognize experiencing the self through the body.

Chronic illness involves managing bodily symptoms for both health reasons and for social reasons, and sometimes these needs conflict with each other (Corbin and Strauss, 1987). Individuals develop various strategies to minimize performance failures and to adapt to body limitations. Individuals might struggle against their illness in the hope of regaining past identities; they objectify their bodies and distance themselves from them. This attitude might progress into a struggle with illness whereby individuals attempt to maintain their bodies and lives as normal as possible, eventually integrating new bodily facts into their self concepts and lives (Charmaz, 1995). This discussion demonstrates the various potential relations between the self, identity, and body.

Charmaz (1995) used the term *adapting* to describe the process of adjusting one’s life and self to bodily losses and limits and to resolve the lost unity between body and self. This idea of unity between body and self is subjectively defined, and may be repeatedly lost and reconstructed through various stages of illness. When individuals are able to stop objectifying their bodies and let go of the need to master their bodies, they can become more open to bodily experiences and to attending to bodily cues. As the individual with an illness becomes comfortable with the altered body, she or he may begin to unify the altered body and self.

In summary, the body is an important part of a discussion on self, identity, health, and illness. In healthy individuals, the body and self are seen as reflexive aspects of one wholeness, but in individuals with a chronic illness, the body and self are considered disrupted. The meanings of this disruption and of the changed body are influenced by social and cultural themes. Chronic illness requires that attention be given to the meaning of the body. This literature on chronic illness and the body is a valuable beginning of a sociological exploration, yet studies which further conceptualize the theoretical processes and meanings of embodiment in relation to identity, self, and chronic illness would add to this emerging body of literature. Furthermore, the condition of diabetes has not been explored using a theoretical framework of identity and embodiment, and thus deserves study because of the constant and unique body management which this condition necessitates.

2.4 Narrative and identity

Connelly and Clandinin's (1990) explanation that narrative is both a phenomenon and a method is helpful in understanding the various ways that narrative is used in theoretical and research studies. Narrative refers to the structured study of experience and to the process of inquiry (Connelly and Clandinin). A theoretical discussion of narrative and its relation to identity will be explored in this section. A discussion about narrative methods will be further elaborated in the method section.

The study of narrative is an exploration of the stories that people tell as a means of understanding the way that they experience the world (Connelly and Clandinin, 1990). There are various understandings of narrative, but there is a general agreement that stories and

storytelling are pervasive and we live immersed in narrative (Maines, 1993; Polkinghorne, 1988). It is suggested that people are simultaneously telling, retelling, and reliving stories (Connelly and Clandinin). This is done as individuals reflect on past experiences within the context of their present selves and reshape the stories in relation to new experiences and different situations. This process is conducted with the intention of organizing one's experiences in a coherent manner as an individual makes sense of his or her life by interpreting oneself to others (Kohler Riessman, 1993; Robinson, 1990). The contextual and experiential contingency of narratives makes it difficult to grasp their meanings and also contributes to the existence of conflicting narratives (Polkinghorne).

Somers (1994) reconceptualized narrative from a representational form traditionally used by historians, to a social epistemological and ontological form. Ontology is the study of the nature of being and of reality. Epistemology is the study of the nature of knowledge, what constitutes knowledge. Somers outlined four components of a narrative: (1) relationality of parts (2) causal plotment (3) selective appropriation (4) temporality, sequence and place. Somers claimed that narratives "render understanding only by *connecting* (however unstably) *parts* to a constructed *configuration* or a *social network* of relationships (however incoherent or unrealizable) composed of symbolic, institutional, and material practices" (p. 616). The plot connects the parts and gives significance to independent events which individuals single out for attention from the myriad of events, experiences, social factors, and other people that comprise their lives (Somers, 1994).

Using these four essential features, Somers (1994) positioned four types of narratives. Somers' conceptual narrative, narrative identity, will be used in the current analysis. This

concept, as Somers explains, is shaped by ontological and public narratives. 1) Ontological narratives are used by individuals in order to make sense of and to act in their lives. Through the process of organizing events into coherent episodes, ontological narratives define who we are which allows us to know what to do. This then creates new narratives and therefore new actions. Thus ontology and narrative are mutually constitutive. The character of ontological narratives and their role in the construction of the self and identity mean that self and identity are continuously in development in relation to time and relationships. 2) Public narratives are social and interpersonal narratives which shape ontological narratives. Public narratives are associated with cultural and institutional systems larger than the individual. Types of public narratives include narratives of the family, workplace, and the government. 3) Metanarratives are narratives in which we are historically located. Somers claimed that these narratives are embedded in sociological theories although they often exist as pre-givens of social science epistemology. Examples of metanarratives that Somers provided are Enlightenment (trends of thought in the 18th century characterized by reason and science) , Industrialization, Progress, and the drama of Capitalism versus Communism. 4) Conceptual narratives are the concepts and explanations that social researchers create. Somers suggested that the challenge is to create a conceptual narrativity that accommodates the notion that social life, social organizations, social action, and social identities are temporally and relationally constructed through ontological and public narratives. In this way, personal and structural influences are integrated. These ideas are the framework for Somers' position that social life is storied, that stories guide action and that experience is constituted through narratives.

Somers, and other theorists, have positioned the integral link between narrative and

identity. People construct identities by locating themselves or being located within a repertoire of emplotted stories (Somers 1994). Somers advocated the concept of narrative identities because it captures the fluid, contingent and contextual character of identity which is located within places and relationships that change over time. Mathieson and Stam (1995) suggested that conversations become narratives when they are part of the search for personal identity. Similarly, Paul Ricoeur proposed the term narrative identity to describe how the self comes to be through the process of telling one's life story (Frank, 1995). Gadamer effectively used the word dialogue when he explained that experience and story are in a dialogue with each other and that this interaction results in the development of new meanings and the creation of identity (Widdershoven, 1993). The focus on the individual construction of stories is located within the cultural processes involved in shaping the stories as discussed by Somers. Maines (1993) also recognized the individual as a self-narrating organism and that these self narratives are connected to collective narratives.

The connection between narratives and identity explains why stories are a valuable means of understanding experiences in individuals' lives, such as the significant experience of a chronic illness. Kohler Riessman (1993) explained that individuals often tell stories when there has been a gap between ideal and real and between self and society. Chronic illness is such a situation. Narratives play a key role in the experience of illness when individuals' identities and lives are disrupted and some of the old narratives are no longer appropriate (Williams, 1994). The process of narrative encourages individuals to restore the order in their lives that the illness destroyed and to work out their changing identities. Telling stories to one's self and to others reaffirms relationships with the self and with others, and also provides

guidance for others (Frank, 1995).

Narratives both reflect and shape the illness experience (Kleinman, 1988). Narratives are integral to the process of making sense of the past, present, and the future. Diabetes requires individuals to engage in behaviour patterns on a daily basis that demand different ways of being. Narratives, which emphasize the notion of relations, plot, time, and place, and the notions of interconnection and change, are a means of exploring this process and how individuals respond to and shape their experience of illness. An exploration of both ontological and public narratives provides insight into the different and interconnecting levels of narrative which individuals use to construct their identities.

2.5 Identity, self, and the body

The terms identity and self are loosely used; it is difficult for the uninitiated reader to grasp the meanings of these widely used but intangible concepts. An exploration of the chronic illness literature that has used a symbolic interactionist perspective on identity and the self and recent ideas which include the theories of narrative and the body, can produce a clearer and more comprehensive understanding of identity and self. An integration of the various theories can offer a more compelling understanding of self, identity, and the body that incorporates both the subjective and experiential aspects as well as the social and structural forces which shape these phenomena. Kelly and Field (1996) wrote that "identity defines a person as a social object locked into group memberships and social relationships" (p. 245). This idea and specifically the word locked conveys a sense of rigidity. This notion of fixed categories can also be observed in other chronic illness work. Through an integration of

various theorists, it is possible to develop an understanding of self and identity as fluid, dynamic, interactional and continuous projects.

2.5.1 The self versus identity

In reading the literature, it is a challenge to comprehend the meanings of, and differences between, self and identity. Self and identity are differentiated in the literature, but there is a lack of explicit definition of their distinct meanings. The symbolic interactionist framework has been useful in clarifying this distinction.

Charmaz (1987) and Yoshida (1993) defined the self and identity in a similar manner following a symbolic interactionist perspective. Symbolic interactionism claims that society consists of selves who make their social lives meaningful through interaction. Reality is constantly being constructed through interactions as individuals interpret the symbols which develop through interaction (Clark, 1990). Yoshida and Charmaz defined the self as a reflexive, emergent structure which is shaped by both social and personal identities. Personal identity refers to the attributes, actions and appraisals that an individual makes about one's self. Social identity refers to these types of identifications that others make about the individual and which the individual interprets and confers upon the self. Calhoun (1995) conceptualized the interaction between self and identity and also discussed the importance of recognition. Calhoun stated that identity is a major aspect of the project of subjectivity which could be read as the self, and that identity involves the interrelated problems of self recognition and recognition by others. I have interpreted the ideas of identifications or recognitions as a process of understanding, approval, acceptance, and verification. Kelly and

Field (1996) also emphasized the notion of the subjective versus social. They defined the self as a cognitive construct that is developed from ordinary life as individuals perceive their own subjectivity, whereas identity is the public and shared aspects of individuals.

I accept these definitions described above of self and identity provided by Charmaz (1987), Yoshida (1993), Calhoun (1995), and Kelly and Field (1996), and believe that these descriptions share common attributes which are helpful in developing a working definition of self and identity. The self is a cognitive, reflexive, subjective experience. Calhoun's (1995) definition of reflexive is helpful. Reflexivity is viewed as the ability to look at one's self, to choose one's actions and see their consequences, and to hope to make oneself something more or better than one is. The subjective aspect is interpreted here as an individual process of interpretation and perception. I would add to this definition of the self by including a physical sense of self and not only a cognitive aspect. The self is significantly shaped by our identities, or more explicitly, by our personal and social identities, which Charmaz (1987) and Yoshida (1993) described. Identities are social as they are developed through interactions and are constituted both by the recognitions and identifications made by others and those made by the self. Gubrium and Holstein (1995) contribute further to this discussion by noting that the construction of selves shapes the active representation and management of identities, thus how people think of themselves shapes how they attempt to publicly portray themselves in narratives.

Self and identity represent different aspects of an individual's being, but they are interconnected as each contributes to the development of the other. Somers (1994) noted that both of these constructs are in a continuous state of development. The differentiation

between self and identity allows for an exploration of an individual through both a phenomenological, experiential and subjective perspective, and also through a social constructionist perspective.

2.5.2 The narrative constitution of identities

How are selves and identities constituted? An exploration of this question allows for an explanation of how this process occurs and what forces shape this process.

Somers (1994) criticized identity theories which assign meaning to identities by attaching a fixed “essentialist” singular category such as race or gender. Essentialist means that there is a belief that it is possible to identify fixed underlying sources of identity and that the fixed boundaries clarify the conditions for and results of belonging (Calhoun, 1995). Not only do these categorizations exclude the many other fundamental facets of identity, but they also attach their own normative evaluations to their typifications. Somers’ goal is to reintroduce the “categorically destabilizing” dimensions of time, space, and relationality that give a temporal and relational quality to identity. Narrative identity embeds the individual within relationships and stories that shift over time and space. An individual is located at the intersection of ontological and public narratives and it is within these multilayered narratives that identities are formed. These narratives are mediated through the immense spectrum of social and political practices and institutions that make up our social world. Individuals’ actions can be understood according to their location in relationships and the stories with which they identify (Somers and Gibson, 1994).

Whereas Somers used narratives to understand how identities are constructed,

Calhoun (1995) stressed the role of discourses. Discourses are the meanings and language that we use, the way that we think, talk, and write about phenomena. Calhoun suggested that identity is “constructed and situated in a heterogenous field and amid a flow of contending cultural discourses” (p.196). This idea is similar to Goffman’s (1973) concept of role dissensus which describes the existence of multiple ways of performing resulting from multiple cultural and group affiliations, and the chosen way will depend on which ‘other’ is a more valuable audience. Calhoun also critiqued the essentialist notions that individuals can have singular, integral, harmonious and unproblematic identities. He argued that while the essentialist reasoning can at times be instrumental, the difficulties in identity construction resulting from the tension among the various value spheres and discourses must be recognized. These difficulties, Calhoun explained, occur both externally which can be interpreted as social recognitions and also in our efforts to attain a coherent subjectivity. Social discourses about whom it is possible or appropriate or valuable to be, shape how we look at and constitute ourselves. These many contending and socially defined discourses make recognition and non- recognition by others, which is linked to self recognition, problematic. The problems of recognition are significant because recognition is essential for identity construction, which is in turn a vital aspect of subjectivity (Calhoun).

Gubrium and Holstein (1995) also focused on the interactional and discursive practices directed to the self and to others, but their focus is more localized. Gubrium and Holstein viewed the self as being constructed by interpretive actions that use substantive resources of everyday, local, practices. It is through these practices that individuals actively manage their identities. The substantive resources are categorized as locally shared

meanings, biographical particulars, and material objects. Locally shared meanings refers to local cultures which are categories, typifications, and conventions associated with perceivable interpretive circumstances. Local cultures are not fixed but require participants to both reference and enact what is accepted as shared. Biographical particulars recognize individuals' histories, what we have done, been, or experienced. Material resources are objects available for metaphorical construction, they are visible objects that could be used as bases for self representation.

These theories share common ideas although the language used might differ. Selves and identities are constructed within social contexts, and an individual has many selves and identities depending on the particular interpretations and the specific location and time. Although the theorists used different terms, such as discourse versus narratives versus local cultures, the processes involved are similar. In my view, narrative construction incorporates discourses and local cultures but these phenomena are comprehended and integrated through the means of stories. Gubrium and Holstein's ideas of biographical particulars is important because it recognizes the individual's history but Somers also recognizes this in her idea of ontological narratives and the individual's actions being defined according to his/her positioning and understanding of one's self within the existing narratives.

2.5.3 Challenges in the process of self and identity construction

An understanding of the fundamental processes that are involved in identity and self construction leads us into a further exploration of the confusion, conflicts, and challenges that could occur within this dynamic process of self and identity formation.

Gubrium and Holstein (1995) claimed that an individual has many selves which are constructed in different interpretational contexts with diverse manifestations. They employed Goffman's definition of self construction as a process of everyday work located in time and place, but emphasized that this work is tremendously more multisited than ever, and is increasingly occurring in public forums, typically within organizational frameworks. Gubrium and Holstein emphasized the practical boundedness that provides order to the self and did not elaborate on the possible fragmentation that could be a result of the increasing complexity of our lives and the emphasis on living in institutional contexts.

Calhoun (1995) viewed subjectivity and identities as being much more problematic in modern times. Calhoun claimed that if we adhere to Mead's proposition that the sense of self is comprised in relation to significant specific others and a more generalized social other, then we have a challenge when we cannot assume harmony among the significant others or singularity of the generalized other. This lack of harmony is attributed to the existence of multiple cultural discourses and identity schemes as well as social discourses about who it is possible or valuable or appropriate to be. Calhoun viewed identities as being in a condition of fragmentation, incompleteness, tension, and contradiction.

Somers (1994) also recognized the existence of conflict and tension. She suggested that the location of the individual at the intersection of various narratives could contribute to identities that are multiple, ambiguous, fleeting, and conflicting. Somers not only recognized this as a result of multiple narratives, or discourses as Calhoun would say, but she also discussed the influence of the existence of a limited availability of narratives. The existing repertoire of narratives is historically and culturally specific and is influenced by the

distribution of power. Somers saw confusion, powerlessness, and victimization as some of the outcomes that could result from an inability to relate certain experiences with available cultural, public and institutional narratives.

Once again, the theorists used different words, but the ideas are similar and represent an understanding of the complexity of self and identity construction. The construction and interpretation processes involved and the existence of many sites, discourses, and narratives, demonstrates the many and different selves and identities that can be part of an individual. The values attached to narratives, the complexity and multitude of narratives, and the potential for these multiple narratives to be limited if the available narratives do not meet one's expectations of one's self and identity, can lead to confusion, fragmentation, and tension in individuals as they struggle to achieve a sense of coherence and understanding of themselves.

2.5.4 The relationship of the body to self and identity

It is interesting that the body is not discussed in the ideas of identity and self that have been previously explored. When one thinks of a self or identity, it seems logical to think of an embodied person, but the body is often not given recognition. Calhoun (1995) did comment that the modern perspective of identity views the individual as a disembodied cognitive subject, but does not further elaborate on how the body can be introduced into a conceptualization of identity and self. Turner (1992) suggested that the identity of individuals cannot be separated from their embodiment within the interactional situation, as is observed in Goffman's discussion of the presentation of self being dependent on our control and

representation of our bodies. Turner has provided insight into the theoretical positioning of the body and why it is a critical area of exploration.

Turner (1992) suggested that ontologies of the body tend to be divided around foundationalist and anti-foundationalist frameworks. Foundationalist frameworks are focused on understanding the body as a lived experience, the phenomenology of embodiment, the complex interaction between the organic systems, cultural frameworks, and social processes, and how the biological conditions of existence intrude upon the everyday life and macro organization of populations of people. Anti-foundationalist frameworks view the body as an effect of social discourse, the body is seen as a discourse about the nature of social relations, or a system of symbols, or as a social construction of power and knowledge in society.

Turner (1992) explained that we do not have to choose between these different orientations, but it is possible to have some theoretical reintegration because each theory is addressing different analytical questions. Turner used German terms to demonstrate the different possible ways of talking about the body. "der Leib" refers to the animated, living experiential body and "der Korper" refers to the objective, exterior and institutionalized body. These different words demonstrate how embodiment is both personal and impersonal, objective and subjective, social and natural. Frank (1991) also demonstrated a mixing of positions in his suggestion that the body is constituted in the intersection of an equilateral triangle whose points are institutions, discourses, and corporeality.

The study of the body is both interesting and essential to a discussion on identity and self, particularly when a chronic illness is a part of life. An appreciation of the theoretical positioning of the body and the various levels of analysis is a necessary starting point for this

type of exploration as it will provide an approach for research in chronic illness, the body, self, and identity. The body nicely links the notions of self and identity because just as the self and identity allow for an exploration of the subjective and the social, so does an analysis of the body allow for an exploration from both of these perspectives.

2.5.5 Application of the theory of self, identity, and the body to the study of diabetes

This discussion on self, identity and the body has demonstrated how these phenomena are constructed both through individual actions and experiences and also through the influence of social processes and forces. This theory can be used to explore the experience of chronic illness. The subjective and social elements involved in self and identity, the continuous construction process, the elements of relations, time, and place, the available narratives and the many aspects of identity and self, provide a context for understanding the complexity of the relation between chronic illness and self and identity.

In the experience of chronic illness, it is possible to view the body from various theoretical perspectives. Turner (1992) suggested that an appreciation of the body allows for an understanding of the experience of illness as not merely being an attack on one's instrumental body, but as an extreme incursion into one's embodied selfhood. It is possible to explore this area from the perspective of the living, experiential body which feels and experiences the illness, and from the perspective of the body as an effect of discourses which would look at how bodily behaviours and management reflect social discourses.

This thesis builds upon ideas of previous studies in the area of chronic illness and the

self, identity, and body, but the major focus is on using the theory of Somers (1994) and Calhoun (1995) to integrate new theoretical perspectives with the everyday experiences of the respondents. The definitions discussed of self and identity and the construction of these phenomena as reviewed in this section, as well as Turner's theory of the body, will be used in this thesis. The focus of analysis on the self, identity, and the body, within the context of living with diabetes, will be on the individual experiential, subjective level and also the way that these phenomena are constructed through cultural influences.

2.6 Diabetes

The importance of exploring the experience of living with diabetes from the perspective of those who have diabetes has been recognized, but the literature in this area is limited. This body of research is small, but the results demonstrate the value of this type of research and the need for further research. The current study builds upon previous research and addresses new ideas. The focus in previous studies included the challenges involved with the diabetes management routine, an understanding of the strategies implemented to deal with diabetes, conceptualizations of the process of living with diabetes, and conflicts between the personal and institutional realms of diabetes management.

Callaghan and Williams (1994), Kelleher (1988), Maclean and Oram (1988), and Peyrot, McMurry, and Hedges (1987), have explored individuals' perceptions of living with diabetes and the challenges with which they dealt. Maclean and Oram examined the personal and social aspects of having diabetes. Their research covered the initial stages of experiencing symptoms and learning about the diagnosis, the processes of learning to live with the

condition, and how individuals did and did not integrate the demands of diabetes into their everyday lives. Much of the research on living with diabetes focused on the process of learning to cope. Individuals had to deal with the conflicts between diabetes management and daily practices and to make decisions about how to balance diabetes demands with other needs. Some of the difficulties described were the unpredictability of blood sugars, restrictions and regimentation resulting from diabetes, the ongoing long term nature of management, loss of spontaneity, and uncertainty concerning long term complications (Callaghan and Williams; Maclean and Oram; Peyrot et al.).

Callaghan and Williams (1994) explained that management approaches ranged from relaxed to vigilant and varied for each facet of diabetes management and over time. Peyrot et al. (1987) discussed individuals' development of their own personal stock of knowledge about their condition resulting from their physical experiences of diabetes and the problem management involved in deciding how to manage diet and to prevent hyperglycemic and hypoglycemic reactions. Maclean and Oram (1988) described the learning process as involving trial and error experiences, assessing the limits, and using self monitoring practices, to help achieve control.

Callaghan and Williams (1994) concluded that the participants in their study were managing their diabetes within the context of other daily activities. Most individuals dealt with the planning demanded by diabetes and controlled how invasive they allowed their diabetes to be, which allowed them to pursue their activities of everyday life. Peyrot et al. (1988) discussed the various lifestyles their participants developed in relation to the diabetes: the "tyranny of tight control" and the "freedom of relaxed control". Peyrot et al. claimed that

the cycle of adaptation changes over time. Maclean and Oram (1988) concluded their findings with a discussion on the significance of the concept of control. They explained that each individual needs to find her/his balance between her/his personal and diabetes needs, and that acceptance of diabetes and the power of diabetes is a crucial element in the integration of diabetes into one's life.

Maclean (1991) contributed to the nutrition and self-care literature through her analysis of patterns of diet related self-care in diabetes. Maclean studied dietary behaviours through an exploration of the meanings associated with them and the contexts in which they occur. Maclean located individuals on a continuum that ranged from strict adherence to diet to no adherence, and suggested that the individual's positioning was influenced by the individual's overall reaction to diabetes and the context in which the individual lived. Maclean grouped influences on dietary management under three categories: individual, diabetes-related, and contextual factors. Individual influences included food preferences, preferred approaches to life management, self esteem and discipline, ease of adjustment to diabetes, and the importance of food and eating. Diabetes related influences involved the severity and duration of diabetes, the unique history of living with diabetes, and an individual's perceived impact of diabetes on his/her past, present, and future health. Contextual influences included social stigma, family support, peer support, professional support, the availability of self monitoring equipment, cultural norms, and occupations. The composition and significance of the influencing factors was unique to each individual. The majority of individuals were in the middle of the continuum, representing a balanced approach to diet management. A smaller group had a more controlled approach while the smallest group had an impulsive approach to

diet, sometimes ignoring it. Many individuals strived to achieve a balance between health, defined according to physiological standards, and well-being, which was associated with subjective experiences and social interactions.

Research has focused on the different perspectives of and languages used by professionals and individuals with diabetes, and strategies that individuals developed to live with their diabetes. Peyrot et al. (1987) suggested that illness experiences were shaped by personal experiences of illness and public knowledge which included health professionals' and lay people's knowledge. They discussed the negotiation of illness which occurs as individuals with diabetes and health professionals negotiate the meaning of their condition and control. These authors discussed the type of conflicts that occurred between personal and professional perspectives, and how they were resolved. Kelleher (1988) identified three strategies to living with diabetes: coping, adapting, and worrying.

Hernandez (1991, 1995) also emphasized the different languages of professionals and people with diabetes, and discussed the process of becoming a diabetic. She suggested that this process involved an integration of the diabetic and personal selves. She identified three stages. "Having" diabetes was the time following diagnosis, whereby individuals had pieces of knowledge, and the focus was on being as normal as possible. The "turning point" involved an event that initiated a reassessment of the diabetes in the context of one's life. The individual consequently changed from having diabetes to living with diabetes, which involved a deeper understanding of diabetes and an increased consciousness of the body in relation to the diabetes. The "science of one" phase was marked by individuals focusing on living without risking their diabetes. Hernandez claimed that the focus of living with diabetes had an internal

reference, that diabetes was an integral part of the self. Hernandez's initial effort to incorporate the self into an understanding of diabetes, and her discussion of the implications of her results for diabetes education, are important and interesting, but her linear process presents a different perspective than the multilayered, fluid, evolving notions of diabetes and the self presented in this thesis.

Heather Nicol (1990) conducted a semiotic reading of women's discussions on diabetes management. Through the semiotic approach, which involved an exploration of the metaphors and sets of opposition, the theme of depersonalization emerged. This theme represented a set of oppositions between the institutional and the personal. These oppositions included the mind versus body, reason versus feeling and emotion, technical versus natural, and external versus internal. There was imbalance and tension between the institutional and the personal. Laughter was used as a means of dealing with this disparity and to release the resulting tension.

The insights gained into the specific aspects of dealing with the management of diabetes are important and form the foundation for further analysis on the meaning of diabetes. While some of the earlier studies explicated the behaviours and feelings associated with the management routines, it is hoped that the current study will provide insight into the individual and social processes shaping these behaviours. The studies by Nicol (1990) and Hernandez (1991) represent initial efforts to study language used, stories told, and the process involved in living with diabetes within the context of the self and institutions. The current study builds upon these studies and applies a different theoretical perspective of diabetes and the self, identity, and the body, using narrative as an alternate method.

In the existing literature about diabetes, there is a general lack of integration between health professionals' research and the theory of social scientists, which Nicol's (1990) study begins to address. It is hoped that the use of theoretical frameworks to explicate everyday living with diabetes can further our understanding of the complex processes involved. Theory and practice need to be integrated to inform each other and to further our knowledge. Thus, in the current study, living with diabetes has been studied within theoretical contexts that have been applied to other chronic illnesses but not specifically to diabetes, and also within theoretical contexts that have recently been developing.

The use of narrative theory to understand individuals' constructions of identity and selves within the context of chronic illness has been applied to certain conditions such as cancer (Mathieson and Stam, 1995), and rheumatoid arthritis (Williams, 1984), and the experience of diabetes within a Dakota (Sioux) community regarding cultural history and identity (Lang, 1989), but not within the context of the population studied in the current study. Certain themes might be apparent across chronic illnesses, but it is necessary to study the personal and social experience of each condition separately because each condition has unique characteristics that will influence the meaning of living with that condition. While the theory of identity and self has been used to study the experience of chronic illness, once again, this framework has not been extensively applied to living with diabetes, and the theory of self and identity has been developing in an effort to further elucidate the processes involved. Using theories of identity and self to explore the experience of diabetes can illuminate the context within which diabetes behaviours are manifested. The notion of embodiment has also not been explored extensively within the context of diabetes. Diabetes demands constant

body management and control and thus an attempt to capture what it means to live with and manage diabetes necessitates an exploration of the meaning of being and having a body that is problematic.

The theories that we use to understand processes of everyday living with diabetes informs the way that we understand and think about this experience and can therefore influence interactions and interventions in both social and medical contexts. The self, identity, and the body were all chosen as areas of focus because of their surmised integral connection to diabetes and to each other, and the belief that a framework which integrated all of these constructs would provide a more complete picture of the experience of diabetes. It is hoped that the current research which builds upon ideas developed in earlier work concerning the challenges involved in diabetes management but further links these ideas to sociological theory, will expand our understanding of the complex processes involved in living with diabetes.

3. METHOD

A narrative analysis method has been used in the present research. A review of the literature relevant to narrative research methods will be discussed, followed by a description of the use of narrative methods specific to this research project.

3.1 Review of narrative methods

Narrative is an emerging area, and has been defined in different ways by different people. A review of the literature has demonstrated that there are not specific guidelines on how to use narrative as a method. Researchers have the flexibility to adapt narrative to their particular purposes, providing that they provide a logical explanation for and of their approach.

Narrative is a process of interpretation, and the stories generated exist at various levels. There are individuals' personal narratives which are shaped by experiences and by stories told about those experiences. The research interview process is a construction of another shared narrative between the interviewer and the participant. There are research narratives, which involve interpretation of the text (Connelly and Clandinin, 1990). The researcher must recognize that different interpretations of the text are possible (Polkinghorne, 1988). The stories selected and the lens of interpretation will depend on the particular research question and theoretical orientation. It is a research challenge to represent the continuous and complex nature of the stories being told and retold (Connelly and Clandinin).

Narrative focuses on language because language is the foundation upon which meaning is built. Language is socially constructed; language "filters and organizes

information from the physical and cultural realms and transforms them into meanings that make up human knowledge and experience' (Polkinghorne, 1988, p.158). The study of language in illness narratives is an exploration of how individuals interpret their own experiences and how these are influenced by cultural and historical influences. Methods of analysis can be viewed as a continuum of degree of detailed focus on language. On one end of the spectrum is a linguistic focus on the structural aspects of a story, whereby each pause, word, line, or phrase would be analyzed. The other end involves a broader analysis of the whole story and the underlying themes and social and cultural processes (Connelly and Clandinin, 1990; Kohler Riessman, 1993).

A microanalysis of the text locates meaning in the structure of the story, and how the story is told. Kohler Riessman's (1993) review of Halliday's, Labov's, and Gee's methods of interpretation presents this style of analysis. Halliday classified three functions of language as a means of interpreting meaning. These are the ideational function which expresses the content of what is said, the interpersonal function which concerns the role of relationships between the teller and listener, and the textual function which refers to the structure of a text, how parts are connected. Labov's analysis involves focusing on the functions of different parts of the narrative which include the abstract, orientation, complicating action, evaluation, resolution, and coda. Gee focused on how a story is told. He analyzed aspects of speech such as the pitch, pauses, and stanzas (Kohler Riessman, 1993). These approaches might be useful for certain purposes, such as studying the interaction between people, but are not applicable for the present purposes of explicating the construction of self and identity which involves a broader analysis of content, themes, and structure.

Connelly and Clandinin (1990) proposed an exploration of a story's structure according to the plot, place, scene, and context, as a means of uncovering its meaning. Maines (1993) proposed three necessary elements of narrative. Events must be chosen from the past with the intention of focus and interpretation, these events must be changed into story elements through the use of plot, setting, and characterization that give structure, meaning, and context to the events, and a temporal ordering must be created to provide tempo, duration, and pace. These devices are helpful tools for interpreting narratives.

Kohler Riessman (1993) advocated the structural approach and critiqued a study conducted by Ginsberg on right-to-life and pro-choice activists. Ginsberg identified in women's stories a process of individual transformation as the key force in shaping political consciousness. She differentiated between a story which is a causal narrative of a life and a plot which is a focus on the unexpected turns in a narrative that highlight differences from the conventional story. As Kohler Riessman said, the focus is on locating the turning points that "signal a break between ideal and real, the cultural script and the counternarrative" (p. 30). Although Kohler Riessman is critical of Ginsberg's approach to narrative, this method of looking at the whole story for signs of individual transformation and significant turning points shaping an individual's identity can be valuable, and can be applied to the study of diabetes and identity.

Narrative research methods are emerging in the study of health and illness. The dedication of a whole volume of *Social Science and Medicine* (volume 38, number 6, 1994) to narrative research demonstrates this developing field. In the research reviewed, a clear distinction is not made between narrative as a theory and as a method, which contributes to

confusion in how it is being used.

Mathieson and Stam (1995), in their study “Renegotiating identity: cancer narratives”, demonstrated how cancer patients used narratives to construct a changing identity in response to various stages of their illness. They suggested that conversations become narratives when they are part of the search for personal identity and they provide one’s life with meaning and a sense of direction.

Ian Robinson (1990), in his article “Personal narratives, social careers and medical courses: analyzing life trajectories in autobiographies of people with multiple sclerosis”, demonstrated how narratives were used by individuals to place illness in a temporal and coherent context. The data for his study consisted of written accounts requested from members of a self help group for people with multiple sclerosis. His method involved an analysis of the narrative macrostructure which was defined according to categorizing the coherence and direction of an individual’s behaviours in relation to one’s goals as progressive, regressive, or stable. This type of analysis is restricted because it fits the narratives into a limited structure.

Gareth Williams (1984) in “The genesis of chronic illness: narrative reconstruction” studied individuals’ narratives as a means of understanding how individuals interpret the causes and effects of illness. These narratives involve explanations that draw upon past experiences and future goals and that incorporate the body, self, and society. Williams explained that narratives have both causal and functional components; they help interpret discontinuities and construct a sense of order. Williams presented three individuals’ stories about their lives with rheumatoid arthritis, and used a combination of their quotes and his own

analysis to position his findings in an interpretive framework. Williams acknowledged that the three cases are not “representative”, but he argued that they represent an important element of the experience of illness.

The theory on narrative methods and the various approaches found in the research literature, demonstrate the many ways of interpreting and applying narrative methods. The result is both confusion and potential flexibility. The methods chosen for this particular research analysis were shaped according to the particular goals of the project and drew upon the theoretical and research literature of narrative. An effort was made to adhere to the rigours of narrative analysis as described in the literature in an effort to strive for an appropriate level of validity.

3.2 Criteria for evaluating narrative

Connelly and Clandinin (1990) suggested that criteria for the conduct of narrative are being developed, and each researcher needs to identify and defend the criteria which are most appropriate for her or his work. Consequently, I have selected various ideas concerning the soundness of a study from different sources, with an emphasis on discussions specific to narrative research, that are applicable to the current study.

Polkinghorne (1988) used the concept reliable to refer to the dependability of the data. This concept relates to the context of the interview and how information was gathered. Since I did not conduct the interviewing I cannot describe this process through personal experience, but can present the established protocol and can strive to identify and discuss how the interviewer and context might have influenced the interview transcript.

Connelly and Clandinin (1990) suggested that narrative explanation develops not from the notions of cause and effect, but from the overall narrative. While they emphasized the need for the analysis to be generated from the whole, they also stressed the importance of providing experiential detail. It is this detail, they claimed, that provides the authenticity of research findings. In my analysis and presentation of results, I strived to achieve this sense of whole while also providing particulars that would encourage plausibility, a feeling that invites the reader to recognize and affirm the happening of that particular occurrence.

Polkinghorne (1988) used the term validity to refer to the strength of the analysis of the data, that it is well grounded and supportable. In a similar context, Kohler Riessman (1993) used the term persuasiveness which she defined as an interpretation that is reasonable and convincing. Kohler Riessman suggested that a way to achieve persuasiveness is by supporting theoretical assertions with evidence from informants' statements and by considering different interpretations of the data. In an attempt to achieve validity and persuasiveness, I integrated quotes from the respondents with theoretical positioning in the analysis and continuously shared my interpretations of the data with others throughout the interpretation process.

Lincoln and Guba (1985) used the term transferability to replace the concept of generalizability. Lincoln and Guba suggested that it is necessary to provide a description of the time and context in which results are grounded to enable others to conclude whether the findings could be transferred. An attempt has been made to describe the context of the subsample chosen for the current study. A sample size of four is small and limits transferability, but it is hoped that the framework developed through this analysis will serve as

a foundation for further study with a larger sample.

Polkinghorne (1988) used the term significance to refer to the importance and meaningfulness of the data. Kohler Riessman (1993) used the term pragmatic use to describe the use of a study for others' work. Through a discussion of the gap that the current study is attempting to address, how the interpretation was conducted, and the relevance of the results for further studies and for diabetes care, it is hoped that significance and pragmatic use will be achieved.

3.3 Goals of study

The goal of this research project is a macro narrative analysis, thus focusing on themes and stories, rather than on the detailed micro narrative analysis. Within this macro analysis, various questions were asked. One level of analysis has been the individuals' stories about their lives and diabetes; what do they tell? why do they tell these stories? how do their stories change over time, and how do these stories interact with the construction of their selves and identities and the meaning of their bodies? The second level of analysis is on public narratives (Somers, 1994); how do public narratives shape the ontological narratives of the individuals? Which common public narratives are found within the individuals' own narratives? This analysis focuses both on the content and on the process of story-telling. Why is story-telling central and necessary for social life, particularly in the experience of chronic illness? How is storytelling both an individual process and a shared experience? The research interview as a whole, and individual stories within the research interview were means of exploring these questions.

3.4 Data

The data used for this thesis are part of a data set from the Living with Diabetes project directed by Dr. Heather Maclean. This project involved interviews with individuals who had either insulin dependent or non-insulin dependent diabetes mellitus. The interviews, conducted in the middle 1980's, were unstructured, whereby individuals were encouraged to discuss issues that were personally significant to their daily living with diabetes. The original sample of individuals with IDDM consisted of 34 people, 19 women and 15 men, ranging in age from 20 to 76, with a range of 1 to 39 years since diagnosis. The number of interviews ranged from 1 to 5 with an average of 3 per participant. The interviews were tape recorded and transcribed. The transcripts from a subsample of the IDDM group are the source of data for the current analysis.

3.5 Sample

Four women from the original sample were chosen purposively as a subset for the current study. Pat and Jane (pseudonyms) were initially chosen because previous experience with the data by the principal investigator demonstrated their strong ability to verbalize their experiences, which would allow for an insightful analysis. Sue and Barb (pseudonyms) were purposively chosen because of the different length of time that each had been living with diabetes. A decision was made to focus on women in this study in order to have a homogeneous gender sample with the hope of limiting the scope of analysis. It would be interesting to study the role of gender in the experience of diabetes, identity and the body, but due to time limitations, it was not feasible in the current analysis. The women ranged in age

from 25-34. This particular age range was chosen because it was thought that this stage of transition to adulthood involves significant changes, such as those related to relationships and career choices, which would have important implications in terms of one's identity. One woman was married at the time of the interviews, and none of the women had children. All of the women were dealing with the role of the diabetes in relation to various dimensions of their lives including work, relationships, social activities, and personal growth and space.

A focus on young adult women who have lived with diabetes for various durations will hopefully provide insight into certain identity themes which might apply to other women's lives who are experiencing diabetes and similar lifestage experiences and have similar backgrounds. It is possible that the themes and concepts developed through this study might apply to other women with different backgrounds, but further study is necessary to explore this possibility.

Concerns about the size and characteristics of the sample will be discussed in the critical reflection section.

3.6 Interviews

The data for the current study consists of transcripts of interviews conducted for the study Living with Diabetes, and thus it is necessary to review the earlier interview process in order to position the data collected. The initial plan was to interview each participant 3 times in order to establish a comfortable rapport conducive to the sharing of experiences and emotions. The actual number of interviews ranged from 1 to 5 per participant. The number of interviews conducted was mainly influenced by how many meetings were needed for the

participant to feel that she/he had thoroughly discussed her/his experiences. All interviews were tape recorded and transcribed.

The interviews were unstructured and the main role of the interviewer was to encourage participants to discuss personally important issues related to her/his experience with diabetes. Probe sheets with suggested topics and questions were sent out prior to the first interview and were provided at the end of the first and second interviews to help participants remember or reflect upon certain aspects of their experiences (see Appendix B). The suggested topics were identified through a review of the diabetes literature, and interviewers were instructed to clarify to participants that they were welcome to ignore the topics that were not relevant and were free to discuss their experiences in a way with which they felt comfortable. Interviewers had lists of sample questions for each interview but these were only to be used as sources of ideas and were not to be taken into the interview or used unless it was appropriate. The specific direction of the discussion was supposed to be determined by the experiences that the participant chose to share. In addition to the probing questions, interviewers used summary statements to confirm a correct understanding of the participants' comments and asked questions to clarify unclear comments.

The interviewer's main role was to allow the participant to reflect on important aspects of her/his experiences. The interviews were not specifically positioned as an opportunity for participants to tell their 'stories' of diabetes. Despite the initial intentions, the data were analyzed for their suitability for a narrative analysis, and following this successful pilot study, the data has been approached from this perspective in this analysis. Each respondent in the subset of this study participated in a range of two to four interviews. Three

different interviewers were involved in the interviews of the four participants in the current study. The interviews were transcribed verbatim and the tapes were destroyed for reasons of confidentiality. The data for this thesis can be viewed as a type of document.

A discussion of the limitations of the interview process will be further discussed in the critical reflection section.

3.7 An overview of previous interpretations of the data

The data used for this present research have been previously analyzed. The results from these analyses were the basis of a book titled "Living with Diabetes" by Heather Maclean and Barbara Oram (1988), a doctorate thesis titled "The personal meaning of chronic illness within the context of everyday life: a case study of the experiences of people with insulin dependent diabetes mellitus" by Barbara Oram (1992), a masters of science thesis titled "The experience of diet in living with diabetes" by Sandra Horney (1986), and a journal article "Patterns of diet related self-care in diabetes" by Heather Maclean (1991). These publications have made significant contributions to the field of diabetes. It is believed that another analysis of the data using a different theoretical perspective, asking different questions, using alternate methods, and a different sample subset, has provided unique results that will further our insight into the experiences of living with diabetes. A description of the earlier analyses and focuses, and a comparison to the present research, will demonstrate the meaning gained from the current interpretation of these data.

The book "Living with Diabetes" (1988) is a description of common issues related to the experience of living with diabetes that reflected concerns of many of the individuals

interviewed. The sample used for this analysis consisted of individuals with both insulin and non-insulin dependent diabetes, males and females, aged 20-76. The analysis for this book was based on the grounded theory approach. The data were coded to generate themes. In order to gain an understanding of common themes, the focus of this approach was cross sectional. Summaries and vignettes of individuals' experiences were used as a means to convey these central themes.

Many of the themes discussed in "Living with Diabetes", such as diagnosis, learning to cope, the broader impact of diabetes in relation to social interactions, and control, are also central to the present research project, but the level of interpretation differs. The book described general themes in the experience of diabetes that were common across individuals. The scope and breadth of this initial analysis resulted in less attention to detailed within a person analysis. By focusing on a smaller number of individuals, it was possible to explore in more depth the original themes and to generate additional themes developed from a more detailed analysis. The current focus is a longitudinal analysis of individualized processes of living with diabetes.

The current focus differs in that the lens of analysis is the interaction between diabetes, self, identity, and the body. The vignettes in the book do contain significant identity issues, but these were not explicated and discussed. The present research used sociological theory of identity, self, and the body to further explore the meaning of diabetes. Narrative theory and methods was used as a means of comprehending a different type of meaning than that attained through grounded theory. A narrative approach allows for the exploration of the personal meaning and interaction between the forces of the self, others, the body, and illness within an

individual and within larger social contexts. Narratives were used to develop a sense of both the details and the wider picture, in order to develop personal and public narratives which underlay the process of living with diabetes.

“Living with Diabetes” (1988) lays an important foundation for the present analysis. Certain concepts discussed in the book were further explored in the current study to extend our understanding of the depth of meanings and how they are shaped. For example, Living with Diabetes only briefly touched the metaphorical images used by study participants as they described the meaning of their experiences (see pages 116-118 in which the meaning of diabetes is expressed through the metaphor of war.) A more thorough search for and examination of metaphors may add to our understanding of the process of living with diabetes. Thus the current analysis has built upon this initial effort at a metaphorical analysis.

“Living with Diabetes” (1988) also described the experiences, the ‘what’ that occurred. It is hoped that the present analysis will provide more depth by illuminating the background or possible explanations for the experiences. These explanations are situated within the framework of identity and self and how these phenomena might explain the process of integrating diabetes into one’s life. Some concerns described in the book, such as unpredictability of blood sugars, the regimented lifestyle imposed by diabetes, and the difficulties sharing information about diabetes with others, were further explored in the present analysis to understand why these issues are problematic within the context of self and identity.

The present research project involves a sample of young adult women who have insulin dependent diabetes. While an analysis of the broader sample has benefits, the narrower

focus can also be useful. By looking at a particular subset, it is possible to begin to explore certain issues that might be relevant to this particular group. The sample size is small and precludes generalization, but it can elucidate the themes of human experiences which may have relevance for others and can provide the foundation for further exploration.

Barbara Oram's (1992) Ph.D. thesis, "The personal meaning of chronic illness within the context of everyday life: a case study of the experiences of people with insulin dependent diabetes mellitus", was based on the interviews with three young adults from the sample with insulin dependent diabetes. Her objective was to explore how individuals balance illness work, which involves the demands of the diabetes management routine, with the need for a valued and in control sense of self, within the context of social interactions and social norms. Oram recounted three stages of analysis which she did, each progressing to a more focused search for issues related to the interaction between illness work, sense of self, and social contexts. Oram proposed changes to the health care system's dominant perspective on the management of chronic illness in the form of a framework of illness work based on the subjective experiences of individuals with diabetes. Suggested elements of this framework included determining the key dimensions of social normalcy for each client and being sensitive to the stigmatizing potential of chronic illness, promoting choice and flexibility in an individual's work, and recognizing the uncertainty of regulating symptoms.

Oram presented her results using summaries of the individuals' experiences and quotes which illustrated her themes. Oram did refer to issues of the self and the body and discussed concerns about controlling the body, the influence of others, stigma, conflicting forces in the management of diabetes, and the need to maintain a valued self, but her focus was on illness

work and the valued self within social contexts in everyday life. She used her results to argue for changes to the health care system. The present research project expands upon Oram's analysis. Its main focus is issues related to identity, self, and the body, as a central means of understanding the process of living with diabetes. A more extensive use of sociological theory on identity, self, and narrative provides a different level of interpretation and theoretical perspective from that of Oram's. The focus of the present research is to explore how narratives provide insight into both the particulars of diabetes management and the more general implications of having a chronic illness.

Oram used three individuals as the basis of her analysis. She chose these three individuals because they all had diabetes for at least eight years and had achieved some sense of integration of diabetes into their everyday lives. They differed with respect to the types of social relationships in their lives, amongst other issues. They were all young adults, two females and one male. The present research project focuses on four different young adults from the original sample. These results can add to Oram's, because they provide a detailed analysis of different individuals. The present sample was chosen in order to limit the focus to young female adults, with a range of years of diabetes duration, in order to explore the different stages and forces operating in the process of integrating diabetes into one's self and life.

Horney's M.Sc. thesis "The experience of diet in living with diabetes" (1986) was an interpretive phenomenological study whose goal was to understand the personal significance of diet within the everyday lives of people with diabetes. The sample consisted of 10 participants with insulin dependent diabetes, 8 from the Living with Diabetes project and two

others from the back up list for this project. The sample included 6 females and 4 males, with two individuals representing each age decade beginning in the 20's and continuing into the 60's. Horney's analysis involved coding and generating general themes and then specific themes related to diet. The four major themes that formed her analysis were the meanings of diet in day to day living, the personal meanings of diet, the process of learning to live with diet and diabetes, and the influence of others on the experience of diet and diabetes.

The journal article "Patterns of diet related self-care in diabetes" (1991) also focused on diet issues in relation to diabetes. Diet is an important element of the diabetes management routine, but is only one small piece of a much larger picture in the experiences of individuals living with diabetes. Furthermore, the meaning of the diabetes diet can be further understood within the context of the role of food and the body to one's self and identity.

A qualitative research process is shaped by many factors, including the angle of interpretation. It is understood that each text contains multiple meanings and realities. Each reading is valuable and can add different meanings to the phenomena being studied. It is hoped that the present research project has produced a meaningful interpretation that will add to our ways of comprehending the diabetes experience.

3.8 Analysis

The research analysis involves the construction of a research narrative using the stories communicated during the interview process. The analysis occurred in various stages, each attempting to explore different levels and meanings of narratives. During the different stages of interpretation, various theoretical frameworks were used to help explore the interview

narrative. Thus the analysis consisted of a continuous process of data interpretation and theoretical exploration, whereby each informed the other.

The participants' transcripts were initially read in order to gain a sense of the women's general stories. This provided a descriptive overview of who they are, their experiences with diabetes, and some general themes. Following this descriptive overview, a more detailed analysis was conducted which involved an exploration of the language used, with a particular emphasis on embedded metaphors. Since language constructs and conveys meaning, it was believed that this type of analysis would provide deeper layers of meaning.

These initial analyses provided an understanding of the women's experiences of living with diabetes and personally significant issues. The next stage involved a focus on issues related to identity. This was achieved by going back and forth between the literature on chronic illness and identity, and the transcripts. This process allowed for an exploration and application of the sociological theory of identity, while remaining close to the transcripts and examining the stories in the interviews that provided a window into identity issues. Individual stories in the transcripts were bracketed and recombined according to identity themes. The themes were developed using concepts from the literature and ideas that were uncovered through an interpretation of the data. These themes included the body, stigma, preferred identities, introspection, and turning points. Quotes from the individuals were the foundation of the analysis in order to present the individuals' testimonies of living with diabetes. This allowed for a continuous reference to the actual data and enabled reviewers to verify my interpretation.

Upon reaching this stage of analysis, I felt as if I needed a clearer theoretical

framework to position my own ideas which were developing through the data analysis and to integrate the various concepts and themes that I had been exploring. At this time, I returned to Somers' (1994) theory which I had previously read, and searched for further readings concerning identity and the body. Emerging from this study, I found that the combination of theories of Somers, Calhoun (1995), and Turner (1992), would provide a framework to position and integrate the data in a way that I felt captured the meanings I was striving to articulate. Thus, this final stage of analysis involved a development and integration of the meanings of the self, identity, body, and narrative in the data, by continuing to remain close to the individuals' quotes, and using the theories primarily of Somers, Calhoun, Turner, but also of other theorists. The importance of the self, identity, and the body to an understanding of living with diabetes was gained through a focus on the language used, particular stories told, themes in the stories, the process of emplotment and storytelling, and forces shaping narrative construction.

4. DATA ANALYSIS

The analysis of the data has been organized according to the theoretical frameworks previously discussed concerning identity, self, body, and narrative. While these phenomena are integrally linked, an attempt has been made to study each component individually in order to increase our understanding of the importance of each of these elements. The analysis has been organized according to respondent through the use of identical subheadings. While the subheadings are the same, the particulars differed, which demonstrates the usefulness of these categories for describing similar processes but individual results.

The four subheadings comprising the analysis of each respondent are identity, self, the body, and narrative. Somers' (1994) concept of narrative identity as being a temporal and relational construct that is shaped by ontological and public narratives, in combination with Calhoun's (1995) emphasis on recognition and non-recognition, form the theoretical foundation of the subheading identity. Self, as a cognitive, reflexive, subjective, and physical experience is the basis for the analysis under the subheading self. Turner's (1992) encouragement to ask different theoretical questions of the meaning of the body, with a particular emphasis on the lived experiential nature of a chronic illness, has been the basis for the analysis section on the body. Under the subheading narrative, the process of storytelling and the forces of narratives have been explored. While these theories have served as the foundations for the analysis, ideas from other research reviewed were also used to interpret the data.

The findings will now be presented in a case style for each respondent: Pat, Sue, Jane, and Barb. Each subsection begins with a summary of the woman's experience with diabetes.

This individual overview is followed by an interpretation of the participant's experience of diabetes within the theoretical subheadings discussed above. The discussion section integrates the specific findings of each woman into a broader conceptualization.

4.1 Pat

4.1.1 Summary of Pat's experiences with diabetes

Pat was 34 years old at the time of the interview, and was diagnosed with diabetes at the age of 25. Prior to the diagnosis, she had been feeling very emotional and her GP suggested that she might need psychiatric help. Since she was working in a lab at the time she tested herself and discovered "4 plus sugar" in her urine and blood sugar levels which were "off the graph". It took her four days to accept what was happening to her and to go to the doctor. When she finally went to the doctor she was relieved to have a diagnosis, and one which had a physiological explanation.

Pat experienced an 18 month honeymoon period during which time she felt "compliant". She succeeded with her dietary objectives and diabetes management while fulfilling her other life goals. Following this period, Pat "crashed". She struggled with problems in her life related to work, school, and relationships, which caused her emotional stress, and which consequently led to problems with physiological control. Pat expected to have better diabetes management than others, but was forced to recognize that she had the same difficulties managing the diabetes as did other individuals. Pat responded to this crash with behaviours which she labelled as "self destructive". She used food to deal with her feelings and to harm herself. Sue viewed her disregard for her diabetes diet as a conscious self destructive action. During this time Pat experienced back problems which were initially diagnosed as diabetic complications. She called this period the "darkest period" of her life, and felt overwhelmed at the prospect of having to live with these complications for the rest of her life. Pat said that she returned to smoking and gained a lot of weight because she was

anxious and upset and suffering from pain. Fortunately, the back problems were rediagnosed as a herniated disk and corrected with surgery. This event motivated Pat to develop a new perspective towards her self and diabetes.

Pat also switched doctors around this time, which helped her develop a new attitude to diabetes and to take more responsibility in managing it. Pat worked together with her doctor to develop a plan which fit her lifestyle, and which increased her flexibility and therefore her freedom. Pat learned how to experiment with the insulin and to become more in tune with her physical needs. This increased her confidence in maintaining her blood glucose levels within a desired range and in controlling her body for both physical and social reasons. The acquisition of a glucometer enabled Pat to further increase her skills in 'reading' her body.

Pat had to deal with the diabetes within the context of her relationships. She had to decide when and how much information to provide to men she dated, and suggested that she might have expected too much from her boyfriend with respect to understanding her diabetes. In relation to friends, Pat felt that there were two reactions, ignoring her situation or oversolicitousness, and that she was always caught in between these two extremes. Pat's relationships with her family members who have multiple sclerosis and arthritis, and with other individuals with diabetes, were a source of support for Pat and enabled her to develop an identification based on chronic illness.

Pat's experiences of becoming more in tune with her body and her interactions with other people and health professionals were accompanied by introspection into her past and into the meaning of her behaviours. She examined her past life and conceptualized her future goals within the context of having diabetes. She accepted that diabetes was a permanent part

of her, and she was not going to neglect her diabetes, but she was not going to let the diabetes restrict her lifestyle.

4.1.2 Narrative identity

Narrative identities are shaped by an individual's location within multilayered ontological and public narratives. The stories that Pat told about herself and the public narratives with which she identified were explored in order to understand how diabetes can be understood within this dynamic construction of identity.

Medical narratives were a key influence on Pat's identity. There were various narratives within this sphere and the particular ones that Pat identified with changed over time as her relations, self, and experiences developed. Prior to her diagnosis, Pat was feeling very emotional and experienced problems of non-recognition by her physician, others, and her self, meaning that others and her self were not able to identify and validate her experiences. The resulting feelings of confusion and lack of understanding had detrimental effects on her self and identity.

Following the diabetes diagnosis, Pat's identity was validated because she was given social recognition as a patient within the medical system. The medical narratives, which involved the biomedical definition of the physiological process of diabetes, absolved her of responsibility for her illness. "My credibility was established with the onset of my disease....there was no problem at all for me to accept it. Because it validated and it justified the bad time I had been having". Pat felt relief because the medical narratives legitimized and valued the physiological explanation of diabetes. "Actually when I did finally acknowledge it

there was...tremendous relief that there was something physiologically wrong with me....this diagnosis was so much better than the alternative diagnosis which was going crazy”.

The medical narrative of diabetes compliance shaped Pat’s identity. Pat linked the words integrity and compliance together; she felt that she could receive others’ approval and recognition by presenting an identity founded on the valued discourse of compliance with the medical regimen. As Pat experienced difficulties achieving compliance, she recognized that she could not sustain an identity of a compliant patient. “I was the one who just sailed through the whole thing initially, and of course, with the years, it’s harder to sustain a legend and to keep, well, for lack of a better word, to keep your integrity intact”. This experience demonstrates the fluidity of narratives which shaped Pat’s identity, and the need to continuously identify new narratives to help in the renegotiation of one’s identity.

The medical narrative of compliance changed when Pat began seeing a different physician. Pat went from relating to a narrative of the “golden blood sugar rule” to a narrative of medical flexibility and understanding. Her physician provided her with the opportunity to construct new narratives about the meaning and management of diabetes which gave her flexibility and confidence managing the diabetes and enabled her to change perceptions of her self and her identity. The doctor “allowed me to vary my insulin dose with my lifestyle...allowed me to get out of line without feeling that I was failing or that something was wrong with me because I couldn’t keep my blood sugar in line”.

Pat’s family narratives, another type of public narrative, had a significant influence on her identity. Pat’s sister was diagnosed with multiple sclerosis and her father was “badly crippled” with arthritis, “so I’ve got a lot of comparative examples around that make me feel

better about what my life sentence is". Spending time with other individuals who have diabetes also provided this same sense of identity founded on chronic illness. Pat claimed that "...it's only in a group like that usually that you can freely express yourself and be understood....and there's no feeling of embarrassment or constraint when you are talking about it". The experience of chronic illness in the family and belonging to a group of people with diabetes gave Pat support, a strong identification with chronic illness, and a narrative about her own "life sentence".

Relations with friends was another area which formed Pat's identity. Problems of recognition and non-recognition were central to this issue. Pat explained that reactions from her friends involved either "absolute ignorance...or oversolicitousness". "It's [diabetes] is part of me as a person and if you are interested in me, it's something that you should deal with about me. But on the other hand if you overdeal with it you put me in a terrible position. So there is always that swing". This was Pat's narrative of her interpretation of others' reactions, which was shaped by Pat's reflexivity about this aspect of her self. Pat needed the recognition of her diabetes but she did not want others to "overdeal with it". Relations with men she dated was another area where problems of disclosing and recognition arose. She struggled with when and how much of this part of her self to share.

Public narratives of chronic illness and stigma shaped Pat's personal experiences and narratives. Pat felt that people in general could not relate to her diabetes, "with any illness, healthy people don't like to talk about it....they simply can't relate to it because the experience is just not there". It is possible that these individuals did not identify with the same narratives that Pat had been forced into with the experience of diabetes. Within this public narrative of

chronic illness and stigma, Pat had to learn how to fit her diabetes into her relations with others. She discussed her difficulties talking about her diabetes, learning “when it has to be said and when it doesn’t have to be said”.

Other public narratives which shaped Pat’s identity included narratives about health and diet, and lifestage narratives. Pat focused on the diet aspect, versus the drug aspect, of diabetes, because to her, diet was “normal”. The lifestage public narrative refers to the cultural and social expectations of people Pat’s age. As Pat said, at this time in her life, “it’s when you seek change and seek growth and when you seek differences”. We have certain narratives for each lifestage and we seek to fulfill those expectations.

Pat’s narratives which interpreted her past and positioned her in the present enabled her to construct her current self and identity. She said that she was not going to neglect her diabetes but she was not going to let it restrict her lifestyle. Pat did not want the narrative of diabetes to dominate her identity, and wanted to build her identity within multiple narratives.

4.1.3 Self

Pat’s narratives revealed the process of the self and its integral role in an understanding of her living with diabetes. Pat’s identity shaped her sense of self and was in turn managed according to her concept of her self.

Pat’s “crash” period and the resulting self-destructive behaviours revealed the struggles operating within her self. The destruction of a desired identity of compliance forced a recognition of her self as not being the self that she wanted to be. Pat perceived her failure with the diabetes regimen as a failure of her self. As a punishment, she consciously inflicted

harm on herself through damaging diet behaviours. Pat said that these behaviours were not visible to others and thus she was able to manage an identity that was separate from her perceptions of her self. The ability to reflect on one's self and to interpret one's behaviours and feelings was central to this struggle that was occurring within Pat's self.

Through this same process of reflexivity and subjectivity, Pat was able to change her diabetes narratives and her understanding of her self. The diabetes forced a conscious awareness of the narratives which were defining her identity. Through an exploration of these narratives which existed in her past and present, Pat was able to make sense of her experiences with diabetes. Part of this exploration was a process of introspection and reflection. The process of introspection allowed Pat to reflect on how she was behaving and why, and to see how this affected her self and how she wished to be. Pat said that having diabetes "forced me to stop and look....and the diabetes has somehow unlocked a lot of things for me". She said, "what I was doing as a diabetic wasn't really different from what I had been doing before, led me to realize that there were other things in life that had set me apart. And it was through those things that I had developed the behaviour patterns that I was using in diabetes".

During the earlier phases of living with diabetes, Pat's identity as defined according to others' and her own recognitions was the determining force of her self development. Through a strengthening of her subjectivity, she was able to change her perception of her self and change how she wanted to manage her diabetes in relation to her identity. This change involved an increased comfort and control over the diabetes management in relation to how she wanted to act and how she wanted others to recognize her.

4.1.4 Body

Pat's narratives about her body demonstrated both the complex interaction between her physiological system, cultural frameworks and social processes, and also the social construction of bodily meanings.

Pat's lived body was central to her interpretation of her diabetes experiences. The stories that Pat told about her body were grounded within the context of her self, identity, and social processes. Pat's ability to have a functional body, of which she was in control, in order to perform within social processes, marked Pat's feelings towards the diabetes and her notions of being healthy. Pat began her narrative about the diagnosis of diabetes with a description of a "slow erosion of well-being". The physical and emotional bodily feelings, the labelling or lack of recognition of these feelings by the medical system, and the limitations on her interactions in social processes, characterized this period in Pat's life. Following the diagnosis of diabetes, Pat experienced a "honeymoon" period. Her ability to return to a functioning body that reflected cultural expectations of control enabled her to easily accept the diagnosis of diabetes. Pat said that she has "never been as healthy in my life as I was those first 18 months....I felt better than I'd felt in a long time and it seemed like I could cope with the whole world during that period".

The honeymoon period was followed by a "crash", during which time Pat lost control of her body both physically and emotionally. Pat's failure to manage her body affected her ability to interact with others and also her self. Pat used food and her body to deal with her troubled self, "for me anyway eating is a barometer about how I feel about myself. Okay. And maybe a lack of discipline is a bit too fascist I don't know. It's just that I know that

when I'm putting on weight, it's not good for me physically and it's usually an indication that something's going on. That I'm not dealing with or I'm overdealing with....you have your up and your down periods, and there was a fairly long stretch where I was fairly self destructive". At this time, Pat also suffered back problems which caused her to be immersed in her illness. Her physical self overwhelmed her other aspects of self.

The complex interaction between blood sugars, pressures for compliance, social relations, and reflexivity of the self all shaped her interpretation of her body. This lived experience of diabetes through the body shaped Pat's desire to change her relationship with her body. Through the help of a physician who allowed her to change her narratives about her self, body, and diabetes, and through the acquisition of a glucometer, Pat developed a changed relationship with her body. "What she's [doctor] relieved for me is a lot of anxiety and she's made it all right to do what I need to do. She's made it my decision". By experimenting with her body and insulin, using the glucometer to validate her feelings, having the flexibility with insulin injections, and not expecting perfect control from her self, Pat was able to become more in tune with her body and to increase her confidence managing her body. The glucometer played an important role in Pat's changes, "so I'm not doing it blind anymore....getting instant confirmation that what I'm feeling is the right level". "In most cases if patients are given the chance, and given the opportunity to learn, then they are the best barometers of their own body". Pat changed from struggling against her body to uniting her self and her body. Pat talked about her decreased anxiety resulting from her changed relationship with her body and her no longer feeling "trapped in a box".

The centrality of Pat's physical body to her subjective self and to her identity is

demonstrated through two meaningful quotes. Pat says that “I got it. Period. It’s part of me. Like the colour of my hair and the colour of my eyes. It’s part of my physical makeup. Height, weight, hair colour, diabetes, it’s just, that’s it”. The significance of the physical self is clearly observed when Pat says, “when people show insensitivity to this particular aspect of me it does affect me more than if they show insensitivity to my beliefs or other values. Because I don’t know how to describe it. I mean your values are an essential part of you. But somehow not as tangible as something associated with your physical body”.

The above description demonstrates the lived experiential aspects of the body. Public narratives which define the body are also apparent, particularly that of the body as a symbol of compliance and health. Pat felt pressure to demonstrate perfect compliance because, to her, this was a symbol of integrity. Failure to comply was translated as a failure of the self. Another public narrative is the body as a symbol of control. Through controlling our bodies, we demonstrate control and integrity of ourselves. Pat’s need to control her body for social purposes influenced her need to maintain high blood sugar levels in order to prevent having a low blood sugar reaction in front of others during work seminars. “I allow myself to stay high, because I mean oh god the embarrassment of having a reaction in front of 100 people, would just be more than I could take”. The avoidance of public embarrassment was worth the health risk of high blood sugar levels.

Pat’s narratives about her body linked the subjective and objective elements of the body together and signified how the body contains personal and social meanings.

4.1.5 Narrative

4.1.5.1 The process of storytelling

The interview setting provided Pat an opportunity to construct a narrative that provided a coherence and organization to her experiences with diabetes. Through a process of emplotment, Pat chose which stories to tell, how to tell them, how to connect them to other stories, and provided their context within defined places and times. It was a process of making sense of her experiences with diabetes, providing meaning to what happened in the past and how this has affected her present and possible future self. This was shown through narratives which identified different phases and significant turning points. The identification of turning points and a labelling of phases provided insight into the factors which promote change. The phases which Pat identified included diagnosis, periods of self destruction, and a period of renewal, which were positioned in a temporal framework. "I think maybe the turning point for me was, the problem of feeling just rotten. And really having it nothing to do with my diabetes but feeling rotten and having the experience of feeling so low with no energy and pain and having your life shut down and stuff...I've sensed a new phase being initiated out of that and I guess that's part of the reason is that I had to face that and try to make some kind of adjustment to it. That adjustment was never complete obviously because I got a reprieve". The stories which she chose to tell about the past and the present allowed her to shape her self and identity; how she wanted others and her self to recognize her. The importance of this process was articulated by Pat herself when she said, "it's also through talking and verbalizing things that certain things that are floating around in your mind all of a sudden click in".

The important role of story telling was also demonstrated through the meaning of storytelling within these narratives. How to talk about one's self to others in relation to the diabetes was an important issue for Pat. How Pat talked about herself and expressed her needs contributed to the construction and reflection of her identity. "Anybody with a chronic disease has to be comfortable about acknowledging it appropriately. Like, in the beginning it's very hard. Sometimes you blurt it out in a voice that's twice as loud as you normally speak, or you drop into conversations at the lousiest time. But you learn over time when it has to be said and when it doesn't have to be said".

The process of storytelling involves decisions about what to say, who to talk to, and under what conditions, because the stories told are shaped by and in turn shape one's identity and self.

4.1.5.2 Narrative forces

Pat's narratives demonstrated her existence at the positioning of multiple narratives, the multiple selves and identities in construction, and the existence of conflict and ambiguity.

The multi sided construction of selves was observed in Pat's "crash" period. Pat's identity was founded on her identification with various narratives, and when she experienced difficulties maintaining her identity within these different narratives, she "crashed". She failed in school, at work, and in her physiological and emotional control. All of her narratives which she used to define her self were being destroyed.

The ability to construct narratives to explain the past and to help with the construction of an alternate self and identity helped Pat overcome this crash period. Pat's acceptance of

the chronicity of diabetes and her positioning of it within her narratives is seen as she attempted to balance, integrate, and adjust the various narratives which formed her existence. As she said, “what you are is, you know can take a lot of different factors. There’s always room for adjustments of things and, and I would say that definitely, in the first few years, that, if I was rating the factors affecting me, the diabetes would have had a higher rating than it does now. So, there is an adjustment that you make....and there’s so much else coming in at you from all other sides that’s new, and you know you can’t handle, you’re not sure that you can handle. And so it gets bumped down the list”. Pat sought to position her identity within the myriad of experiences and demands defining her self.

The ability to exist in various narratives and to choose which narratives to be located within enabled Pat to develop her own ontological narratives within the available public narratives. Pat’s claim that she was “so much more than just a diabetic” demonstrates the fact that it is not possible to position fixed essentialist identity categories such as ‘diabetic’ upon people. Pat found herself at the intersection of multiple narratives, of which the diabetic narrative was only one. Furthermore, her ability to choose narratives within the diabetes narrative enabled her to shape her own narrative of diabetes. Her identification with a narrative which emphasized flexibility, experimentation, and quality of life, enabled her to develop a narrative to guide her. Pat said, “you try to set up a routine for yourself. But, you’d have to restrict your life so much to make that routine work, that I personally can’t accept being restricted to that extent. And I think at this point in my life I have recognized that. I’m not a model diabetic patient. I’m not going to stop trying new things....for me, restricting my lifestyle to that extent is just unacceptable. And I pay the price for it”.

Despite this comfort with the existence of multiple narratives and the ability to choose which narratives are hers, Pat continued to experience conflict and ambiguity about her identities. Pat said, “diabetes is always a factor in anything and everything that happens to you...to try and separate it or to look at me without diabetes now is not to look at the whole of me”. “There is an apartness that’s not obvious all right...that you carry around with you”. The existing narratives about chronic illness and the lack of chronic illness narratives which could help in the experience of living with diabetes shaped Pat’s constant struggle with the meaning of diabetes. The complexity of existing narratives and the constant struggle was observed in Pat’s quote, “it’s all a big tangle, and it never, it never stops. There’s never a time when you say, if I do this for the rest of my life, I’ll be fine”.

4.2 Sue

4.2.1 Summary of Sue's experiences with diabetes

Sue was diagnosed with diabetes at age 28, and had been living with diabetes for two and a half years. Sue described initial fear and feeling unsure of herself, and the anger and vulnerability that she experienced. Sue dealt with these feelings by educating herself about diabetes. She appreciated her physician's attitude that diabetes is a condition, and there are certain behaviours she must do to control it. Sue attended a diabetes education program which gave her the tools to manage the diabetes. Her attitude was that she wanted health professionals to provide her with information, and it was her decision how she wanted to take care of her own health. Sue's father and grandmother both had diabetes, but she was not close with them, and did not want to know about their diabetes complications.

During the first year following the diabetes diagnosis, Sue had excellent control. She conceptualized the diabetes management as a challenge to overcome. She followed the routine and achieved desirable blood glucose levels. During the second year with diabetes, Sue began to experience difficulties. Sue got tired of having the disease, and lost her motivation to monitor herself. She found it stressful not having control over the diabetes but she had no energy or interest in making an effort. The threat of complications 20 years down the road was "boring", it did not provide Sue with necessary immediate feedback. Sue had other priorities in life and her health behaviours, such as diet and exercise, were the easiest to neglect. Sue needed outside discipline to motivate her again, and was therefore interested in participating in a study which involved intensive diabetes management, which she hoped would increase her interest in controlling the disease.

Sue was having problems with body management issues involved in the diabetes routine. Sue felt frustrated with the food restrictions and the changed eating habits that diabetes necessitated. Sue had been gaining weight, but did not have the motivation to monitor herself to lose weight. Sue feared having reactions, which were more frequent with tight control, because they were physically and emotionally draining, and interfered with her daily life. She also had difficulties exercising because it precipitated reactions. Sue was angry with herself over her lack of control.

Sue's interactions with others in relation to the diabetes had been both frustrating and positive. She found that general society was ignorant about diabetes, and she had to constantly deal with this. Her husband was very supportive as were her co-workers. Her physician was also a source of support as she was always available to provide information and advice when asked, but did not judge Sue.

Sue did not let the diabetes stop her from having a 'normal' life. She travelled, worked, shopped, etc., but she did complain about the lack of spontaneity resulting from the diabetes routine. She felt angry when diabetes got in her way, but said that the country she lived in, and her personal situation, made having a disease like diabetes easier to live with.

4.2.2 Narrative identity

Sue's narrative identity was located within cultural and medical narratives which emphasized education, control, and independence.

For Sue, the medical narrative of diabetes involved the themes of education and self-care. Sue conceptualized the diabetes as a learning process which involved a gradual

understanding about the necessary behavioural changes. This particular attitude towards diabetes reflected Sue's desired relation towards having a condition like diabetes. "And I think as you have diabetes you learn more, and it's almost nice in a way that you have the initial shock. And it's very much, okay, I have to do this. And as you go along you find out on a weekly, monthly, yearly, basis, what it is you have to deal with". Sue viewed her physician as a communicator of information and not as a listener that Pat had described. "The role of health professionals is to provide information. Not to tell you how to live your life. Not to pass judgement on the way you have lived your life in the past, you know, information only....it's my decision, or any diabetic's decision how I'm going to take care of my health".

Sue initially conceptualized the diabetes as a challenge to overcome, and her goal was to achieve a certain level of glucose control. After the first year of achieving this goal, Sue lost motivation. This could demonstrate that integration of diabetes into one's identity cannot consist of only a narrative of behaviour changes and control. Sue's desire to identify diabetes as a goal could reflect a protection of her previous identity. "When I was first diagnosed the doctor was telling me if I can keep my sugar level under 200 that would be fantastic, so I had a goal. And I did it for a year. And then I just got bored, because it didn't mean anything any more. Well it was to see if I could do it. And then I found that I could do it. So there wasn't the challenge anymore".

The narrative of control shaped Sue's concept of her identity, and Sue had to deal with her belief that she failed to successfully identify with this narrative of control. Sue's identification with the narrative of control as a focus on individual responsibility was illustrated through her frustrations with her husband's baking. Sue's relations with her

husband and her husband's love for baking set up a certain situation with which Sue had to deal. "And my poor husband who does love to eat and does love to cook, will bake things for me, which further infuriates me, cause I don't know why he does it, and he thinks he's doing some wonderful favour for me....and then I feel obligated to eat. Cause if I don't eat I'm gonna hurt his feelings....and it's very annoying". Yet Sue continued to say, "and I think in some ways I'm probably more angry with myself but just directing it at him cause it's easier. I don't seem to be able not to eat all these things I like to eat. I don't have that control".

Underlying Sue's feelings about diabetes is her positioning of herself within cultural narratives of independence. "What you really want to do is help people to help themselves. You don't want to create some dependence on you, or dependence on a book or a report or dependence on anything else, you want to create an independence, a self-reliance". Diabetes threatened this narrative of independence with which Sue identified. "The thing around reactions is the fear...my husband said to me at one point, you really couldn't live alone anymore, could you? And I couldn't, or I'd be frightened to....and I have two reactions to that: one, I'm really happy that I don't live alone and I have someone who cares about me, and he is very aware of what's happening to me; and the other is anger". Sue said that her diabetes is no one else's problem, which demonstrated her reluctance to publicly share this aspect of her, "it's not really anybody else's problem or anybody else's business that you have this condition. Except when it impinges upon what you're doing". Sue was able to adapt this narrative of independence to her management of diabetes in her assertion that it was her decision how she wanted to manage her health. Sue was resistant to recognizing a new narrative which defined her identity, that of limitations to freedom. "The incredible lack of

spontaneity that I now have in my life in terms of running off and doing something....and I resent that kind of thing being taken away”.

Sue did not want to identify with the medical narrative of potential future complications. Sue was not close with her father but had recently learned about his diabetes complications. She did not want this information, nor did she know how to act on this information, demonstrating a reluctance to relate this narrative to her own identity. Her father’s diabetes had progressed. “He’s also having severe problems with his feet....his mother was diabetic and had gangrene, and lost a leg. So, knowing those two things has really put a lot more pressure on me, and fear in me, about controlling the disease. So it’s almost like I’m getting too much information. I felt better about things before I knew what he was experiencing”.

Sue defined her identity within the context of work and society’s narratives of chronic illness and stigma. Sue found that she was constantly having to explain her needs and the meaning of diabetes within these other narratives which were “ignorant” about diabetes. Sue wanted to maintain her identity as shaped by narratives prior to the diabetes. She did not want her diabetes to affect her identity as shaped by her work context, but it was a challenge to keep these identities separate.

Discourses about who or what is valued affected Sue’s perception of herself and the diagnosis of diabetes. Sue wanted to construct her own diabetes and health narrative, but she was still influenced by medical narratives of control and compliance.

4.2.3 Self

It was possible to observe how Sue's self responded to and experienced living with diabetes. Sue was able to look into her self and interpret the meanings of diabetes in relation to her self.

Despite Sue's ability to manage a certain identity in relation to social processes, her self was in a constant state of interpretation, reflexivity, and ambivalence. Sue described feelings of fear and ignorance following the diabetes diagnosis. These feelings conveyed a perception and recognition of the physical and cognitive self concerning the meaning of diabetes. Sue also talked about her constant feelings of anger and vulnerability. "The anger at having diabetes is a recurring thing...and I deal with it as it comes up....having to temper your anger, and live with your fear, and your vulnerability that you didn't have before". She talks about being "tired of having the disease" and this might be a tiredness from both the emphasis on maintaining an identity based on certain behaviours, and also the subjective element of living with diabetes.

A reflexivity also allowed Sue to recognize how narratives that shaped her identity in the past continued to influence her present self and identity. This ability to reflect on the past, present, and future, enabled Sue to increase her understanding of the diabetes in relation to her self and identity, which helped learning about the process of living with diabetes. "I tend to learn and do things quickly and get bored very quickly. And I find it boring now. The regimen is boring....so I've gotta find something else now, and it's a similar thing. But I think that's a character trait that I have". She also explained her feelings of anger that existed prior to the diabetes and that diabetes was just one area amongst many related to these feelings.

“The issue is quite vast or quite big and goes over a lot of things. Diabetes is one of many. I’d still have the anger if I didn’t have the diabetes”.

Diabetes forced Sue to cognitively reflect on the influence of diabetes on her self and to recognize how her self changed but also retained elements from her past. A desire to not have to change her perception of her self contributed to a resistance to changing her identity to incorporate the diabetes narrative. Despite this resistance, Sue was forced into a process of subjectivity, to grapple with emotional and physical feelings resulting from the diabetes which she could not ignore.

4.2.4 Body

Sue talked about her body in a more descriptive versus an experiential manner and more as a problem with no level of unification having yet been achieved. The centrality of the physical self was a condition against which Sue was struggling.

Sue perceived her body as an object separate from her self which caused her much frustration. Sue resented having to be conscious about her body needs and giving so much attention to which foods she ate and how much she ate etc. She said, “the regimen is boring. Having to take one or two needles everyday, having to remember whenever I travel to take all my gear with me. Um, being conscious of what I’m eating, being incredibly conscious of how much I weigh. Being conscious of when I wanna exercise and what exercise I’m gonna do”. Her body was problematic when she exercised because she was prone to having reactions at those times. Her body was also a challenge because her weight was increasing. Sue viewed her body as an object which must be cared for but was too demanding. “And that drives me

absolutely insane, because I feel very frustrated, I don't wanna gain the weight and yet I don't wanna be continually monitoring everything I eat and monitoring everything I do".

Sue's body was conceptualized as a problem and an obstacle to her self and her identity. Her physical self was identified as a force fighting other aspects of her self. The way that Sue talked about diabetes reflected her frustrations, "you don't want something, particularly in the kind of society we live in, that controls your choices. I mean as much as we don't want a benevolent dictator, which in a way, is what insulin is. You know if you're good, then everything is okay. But it's still there and it's still controlling and it's still a priority, that you can't get away from".

Sue's talk about her body seemed to be almost lacking a connection to the self, and was viewed as a separate entity. Yet Sue could not dissociate from her body because her body could not be separated from interactional situations and was connected with cultural expectations about control. She did not want to continue gaining weight but she was also resistant to monitoring what she did and ate. Reactions physically and emotionally drained her and reminded her of the interaction between the body, self, and identity. "I find them very draining like I find I'm emotionally and physically just wrecked....and I'm sure part of that is just hiding because I'm so frustrated that it's happened again".

Sue lacked a motivation to care for her own body and needed outside motivation to manage her body which could signify a resistance to wanting to become in tune with her body. "I really need something to stimulate me or to give me more interest in controlling the disease. The first year I had it, I never had blood sugars over 200, I had excellent control. The second year, this past year and a half really, I've really been up and down like crazy. And, although I

find that stressful I find it just too much of a bother to worry about...I'm frustrated now cause I don't feel like there's a lot I can do so I wanna go into the study, so that I can continue to learn more and deal with it better in my life....and there's some external reason for doing it other than my own self-interest".

The body is viewed as problematic by Sue, with which she must constantly grapple. Sue's challenging relationship with her body serves as a foundation for her experiences of living with diabetes.

4.2.5 Narrative

4.2.5.1 The process of storytelling

Sue's participation in the interview process demonstrated a willingness to talk about her diabetes and to position it into a certain context. Sue had been diagnosed with diabetes two and a half years prior to the interviews. Her narratives provided insight into her interpretation of past experiences with diabetes. What she did and did not talk about, and the particular public and ontological narratives which she weaved together were a window into her desired identity and into her subjective self. Many of Sue's narratives were located within a cultural narrative of control and independence and a distancing from diabetes. In contrast to these narratives, the reflexivity and subjectivity of her self was observed.

The process of talking about the diabetes was not discussed by Sue within her research narratives. Sue's talk about the diabetes was in relation to her resistance to talking about this aspect of her self. Sue's difficulties with talking about her diabetes with others was an obstacle. Having to tell a story about one's self when it was an aspect of one self that Sue did

not want to emphasize was a constant burden. “You’re continually making a decision as to whether or not to tell people you’re diabetic, which really is none of their business, or to try and suffer through and have a reaction which is really uncomfortable, or to leave and have them questioning why you’ve left”.

Sue did not describe a need for talking about her diabetes, which could reflect a need to not talk or could represent her particular location at that time.

4.2.5.2 Narrative forces

Sue constructed her identity by maintaining previously valued narratives, but she could not ignore the role of diabetes narratives in her life which at times competed with these other narratives. Sue prioritized other narratives which defined her identity and viewed the diabetes narrative as conflicting with these and thus overwhelming who she wanted to be. “I feel like there are so many other things going on in my life I just don’t have the time, energy, or interest to monitor it as closely as I did when I first was diagnosed and was really frightenedit takes time and it takes interest...and it’s sort of 15th on your list of priorities...there are so many other things in my life and it always seems to me that ever since I can remember I don’t have enough time to do all the things I wanna do. And, the thing that’s easiest to let go, is your own diet or your own exercise or whatever so you can accomplish these other things.

Sue described her life as “normal”, because she was able to maintain her identity founded on other valued narratives. Despite efforts to prioritize these other aspects of her self and identity, Sue felt stressed over her lack of control, but did not have the motivation or energy to worry about her diabetes. Sue positioned herself within the medical narrative of

diabetes and the cultural narrative of independence, and was not able to construct her own diabetes narrative in relation to other narratives which defined her.

Sue's narratives demonstrate a resistance to the incorporation of diabetes narratives into her repertoire of narratives but an underlying understanding that despite this resistance there was a narrative force that she could not ignore.

4.3 Jane

4.3.1 Summary of Jane's experiences with diabetes

Jane was diagnosed with diabetes at age 17 ½, as she said, “when one wasn’t supposed to”. According to Jane, her parents were shocked and insisted on keeping her diabetes a secret. She felt that they did not provide her with support and treated her as if she were a “porcelain doll”. There were no facilities for people with diabetes at that time in the city where she lived, and she perceived her physician as “cold and calculating”. Jane was initially prescribed a diet management program but she lost weight and was “weak and pained”. Consequently, they admitted her to the hospital and taught her how to administer insulin.

Jane completed high school and moved to another city for college. This move initiated her transition into adulthood, and her taking responsibility for herself. She called her new physician the “driller” because he educated her about diabetes and tested her knowledge. The driller’s teaching was conducted in the third person, and Jane became angry because she recognized that diabetes was happening to her. Jane had difficulties controlling her blood sugars and felt like she had a “working pancreas”, but her physician did not believe her. Jane’s anger about her diabetes surfaced and she had yearly rampages during which time she went on a hunger strike. She always ended up in the hospital but never had her needs met, she just wanted someone to listen to her.

Jane moved to another city and finally met a physician who let her thrash out and release all of her emotions about diabetes. This physician gave her the responsibility for her diabetes management and allowed her to take control. The acquisition of a glucometer

enabled Jane to prove that she had a “working pancreas”. The glucometer was an important tool since it increased Jane’s control of her blood sugars and therefore of her body.

Jane reached the point where she said that diabetes is “part of my life”. She achieved her goals of working, studying, living alone, being socially involved, etc. She proved to herself that she can live with diabetes and still “lead a normal life”.

4.3.2 Narrative identity

Jane’s research narrative demonstrated initial feelings of being immersed in narratives not of her own making or choosing, and then having the opportunity to locate and create narratives that suited her desired identity.

Jane’s family narratives had a significant influence on her identity. The discourse about who or what is valued affected Jane’s parents attitude towards Jane’s diabetes. According to Jane, her family believed that chronic illness was a stigma and insisted on treating her diabetes as a secret. Being located within these family relations resulted in Jane’s perception of being treated as a “porcelain doll”. This description represents problems of both recognition and non-recognition by Jane’s family. Jane felt recognized as a ‘diabetic’ but her needs as an individual with diabetes and her needs as an adolescent were not recognized. The identity of a diabetic that she felt was imposed upon her resulted in her feeling lost and alone because she was not able to locate herself within social contexts and relationships.

The medical narratives of diabetes that Jane was located within further emphasized the stigma of diabetes. Jane felt that the narrative of diabetes did not meet her lifestage narrative, which caused confusion with her identity. Jane said that she got diabetes “when one wasn’t

supposed to...it seemed to me something you get when you reach 40 years old". Jane positioned the medical narratives of diabetes in a negative perspective. She viewed her first physician as "cold and calculating". She called her second physician the "driller" because his medical narrative of diabetes involved only the knowledge aspect, and not the emotional aspect, of diabetes. The "driller" imposed a certain diabetes narrative on Jane and limited her opportunity to grapple with her personal meaning of diabetes. He discouraged her from pursuing her broadcasting career goals and to seek a more "conventional...like nursing or teaching or...or secretarial...so I got all this negative feedback". Jane was not encouraged to develop her own understanding of her identity in relation to the diabetes. She said, "I could grasp the print but I couldn't grasp the emotional. In other words, it was fine in theory but not in practice....when I went to him, in essence I was not the patient. Because everything was done in the third person".

Jane's first years of living with diabetes involved living within a narrative of diabetes as a stigmatizing condition. A lack of recognition for who she was and what was happening to her and a recognition of her as possessing a stigmatizing condition shaped her identity. The lack of relations, her feeling of being forced into certain narratives, her inability to verbalize her own narratives, and the effects that this identity had on her self, all contributed to her identity formation being shaped by others instead of her own needs. "Having it...grade 13, I was just beginning to start going a little outward. So, it just seemed to be one more thing to pull me back inward....I lived in a fantasy world". "I had no release from, nobody said, look so you have it, but you're not a doll. All I heard was this thing, and I could see the kids I went to school with, and life seemed so much easier for them".

Jane eventually found a physician who enabled her to locate herself within an alternate web of narratives. Through listening to the physician's narratives and constructing her own, she developed a new narrative identity concerning diabetes which included taking responsibility and control, releasing herself from the stigma of the condition, and opening herself up to the possibility of going beyond her identity as a diabetic. "There's two ways you could live with diabetes. One, let it rule you, or B, you rule it. And it's your choice...I rule it, it's obvious by taking care of myself I'm letting me rule it, in other words...living, I'm doing all the things despite it".

Jane's narratives that described her diabetes experience were a means for her to explain who she was, how she changed, and her present identity. She said that "not that I want to toot my own horn, but I feel now that I have done something, because I had to thrash it out all by myself...for 8 ½ years I have lived on my own with it". Her present ontological narrative was shaped by her locating herself in the challenges of past and present narratives.

4.3.3 Self

The emphasis in Jane's narratives was more on how others have shaped her identity, and less about her self, about the process of a cognitive, physical, reflexivity and subjectivity. Through her narratives, she related an image of this process being almost shut down during her struggles with diabetes, and then once again opened up when she was given the opportunity to share her own stories.

Jane described herself as a "zombie and numb" following her diabetes diagnosis. It seems as if she was unable to interpret what was happening to her and did not have the

knowledge or insight to look at herself and to imagine how her actions could change the way that she was. She was finishing high school at this time and it might be that she did not have the confidence, support from others, and knowledge that she needed to overcome this struggle. "I just seemed to be still involved in this kind of inertia kind of state. I really didn't know what to do, whether to be angry, sad, happy, delirious, depressed". Is it possible for one's subjectivity to be halted? This is Jane's recollection which might be representative of how she felt, but it would seem that individuals are in a constant process of subjectivity. It is possible that the reflexivity and subjectivity of Jane at this time was confusing and the lack of opportunity to sort through this confusion challenged its expression or recognition.

Moving away from home was a motivating factor in Jane's introspection and her ability to reflect on her self. This introspection enabled Jane to look into herself and her past experiences that helped explain her reactions to diabetes and her present needs. "Well in the sense that things that had been building up inside for a long long time, with the diabetes, with my life prior to it, going away seemed to be the last straw that broke the camel's back".

The discouragement that Jane experienced from others to cognitively and physically reflect on herself continued with her second physician when she moved away from home for college. The lack of recognition by others affected Jane's subjectivity, and internal struggles. A subjectivity and reflexivity was a stimulus for her explosive behaviours which called out for others' recognition. "It was a constant thing, I thought about it quite a bit...and I really didn't quite cope with it, it kind of was there, but not there. I thought about it, it was depressing". "I was continually angry, but it was the kind of things that started digging up old things about things that happened in the past with my parents, so there was this continuous anger, like

enough steam had been building up, and you could see steam coming out of the stack, it's just that the stack can't hold it, so once a year it had to kind of fly off and then steam comes out very gradually but then it blows up again, and then...these kind of situations".

A project of the self is necessary for an ability to reflect on how one was, is and wants to be. The self as an emergent cognitive and physical construct is apparent in Jane's narratives. She was constantly working on her self, struggling to understand who she was, how she wanted to be, and the changes necessary from within her self to enable her to develop her desired self and identity.

4.3.4 Body

Jane's narratives of diabetes were shaped by her experiences with her body. The connection between her biological needs, her social needs, and cultural processes were communicated.

Jane described feeling "weak and pained" following her diagnosis of diabetes. Her body was functionally and emotionally drained which limited her ability to perform in social processes. She talked about dragging herself through school and being a "zombie". The bodily disruption that Jane experienced formed the foundation of her experience and her lack of interaction with others. The new concept of her body, that of an object to control, was also foreign to Jane, "my feeling was, I'll play the rules of the game but I don't like the game". "It was that kind of, almost bewilderment, wondering what to do...you know, plus with having to cope with new things, like you have to have a piece of meat 2 inches by 4 inches by 3 inches, and you know, all these strange and profound things, that you can only eat

so much, and you have to have this at that meal. Very bizarre'. When Jane was admitted to the hospital to learn how to administer insulin, she suffered from an insulin reaction and felt panicky. Through bodily feelings, pressure to objectify her body through management, and feeling estranged from her body, Jane was feeling the impact of diabetes on her self. Her body was the location of her experiences.

Jane felt that she had a "working pancreas" because of her fluctuating blood sugar levels, yet her physicians did not believe her, and laughed at her. Jane was listening to her own body, but felt that others were denying her this intimacy and knowledge of her self. Jane's body control was being threatened by others.

Jane used her body to represent her anguished self within the cultural frameworks of expectations of a controlled body. Her body spoke the language that she was not able to verbally express. Once a year Jane went into "rampages". "I just went on a hunger strike, I refused to eat. Usually I had to...ended up having to go into hospital for control". This bodily behaviour which linked biological facts with social recognition and meaning was a means of Jane asserting her needs. The body was a site of communication and resistance.

Through the help of Jane's physician, the development of her own narratives, and the acquisition of a glucometer, Jane was able to harmonize her bodily needs within the social and cultural context. Jane was given the responsibility for her own body which was key in her taking control. As her doctor said to her, "you look after yourself cause you're living with this". Jane was able to control her blood sugar levels and to feel more confident managing her body. The glucometer was a "health saver", she was able "to learn to detect what is a real significant drop and, which is a danger drop, from just, quote, a normal drop....having it

[glucometer] it gives me more control over my life, I feel with it, I'm living a, quote, a normal life". This biological control was necessary for a successful incorporation of her body into the wider social processes which she struggled against previously through the rampages and hypoglycemic reactions that she experienced. Jane's changed attitude to her diabetes was reflected in her changed relationship with her body. Jane adapted comfortably to a structured schedule of meals, insulin taking, and blood sugar testing, and adjusted her work demands within the context of her bodily needs. She said that she takes her "numbers very seriously".

Jane's ability to integrate her bodily needs, her self, and her social identity was demonstrated by her talking about the diabetes management routine, "it's almost at the point where, it's a contentment of not having to think about it anymore because it's part of your life".

From a social construction perspective, it is possible to argue that Jane's self and identity were being shaped through an emphasis on control of the physical body. Her physicians' emphasis on her physical control through monitoring, diet, and behaviour changes could be seen as a social organization of the self. Consequently, Jane's rampages could be viewed as a resistance to this control. Through bodily behaviours, Jane demonstrated her need to attack these social confines.

Control is a necessary element in diabetes management, and through my own engagement with the data and literature, I believe that each individual needs to construct a personal balance of control which considers and integrates biologic and social needs. This finding was illuminated by Maclean and Oram (1988). The body is the site where control is negotiated, where the diabetes experience is manifested and experienced, and a site for

communication.

4.3.5 Narrative

4.3.5.1 The process of storytelling

Jane's research narrative represents her construction of her diabetes experiences.

Jane's active construction of her narrative was her own process of reflection and interpretation. Much of the emphasis in Jane's narrative was on others' contributions to her difficulties with diabetes and how she managed through her own efforts to reach her present balance with diabetes. It is possible that Jane had a need to develop this identity, and needed to do so by constructing these narratives of others. Jane constructed her narrative through a description of the different phases in her diabetes experiences which were marked by where she was living, her relations with others, and her own sense of self. She used significant turning points to represent a change in her self, identity, and diabetes. One such turning point was her move away from her parents' home which motivated a process of introspection and release. She described this time as "joining the human race....having to deal with the coping, finding strength, adjusting to becoming an adult, and making decisions". Jane's experiences with her third physician was another such turning point. The interview narrative provided Jane with the opportunity to verbally construct her diabetes narrative in a way that gave a coherence to her experiences.

The importance of the process of storytelling was illustrated in Jane's experiences with diabetes. The limited repertoire of available narratives and being given the opportunity to construct one's own ontological narratives through an appropriation of available public

narratives was revealed through Jane's narratives.

Jane's interview narrative contained numerous references to her need to verbalize herself. She says her parents "had the hush word, that was forbidden word you don't bring up the subject. I did it but you didn't talk about it". "What I needed most was somebody to talk to". "I wanted somebody to sit down with me and explain to me or let me discuss some of that anger, why I feel, how it's affected me". Jane was not given the opportunity to verbalize her own narrative. Narratives are instrumental to restoring order and making sense of a disjuncture. Being able to construct her own narratives would have enabled Jane to make sense of her experiences with diabetes and to develop her identity and self. Jane's rampages were a means of crying out for the chance to be listened to, but this need was not met. "I wanted somebody to sit down with me and explain to me or let me discuss some of that anger, why I feel, how it's affected me".

The physician was Jane's "witness". He was the first individual who allowed Jane to "thrash out", he was a "friend" who "listened" to her. Jane "cajoled and screamed and cried....discussed things openly with him". He "just let me thrash out all the things that should have been thrashed out". This significant outpouring of feelings was a turning point in Jane's self and identity within the context of diabetes. By talking about the past, selecting and connecting events and interpreting them, looking into her self, and explaining her own needs, Jane was beginning the path to shaping her own ontological narrative. This helped her define who she was and how she wanted to be and which narratives she wanted to locate herself within.

Another key development for Jane was her comfort in talking about her diabetes in

general. This talking could demonstrate that Jane was willing to allow others to identify the diabetes with her identity. Jane comments, “and not really being upset when people ask you, you know, do you have it? Like point-blank. I don’t mind. I say yeah, but I don’t go around telling the whole world I have it, I mean if someone sees my Medical Alert bracelet and says is it for diabetes I say yeah. You wanna know more about it I’ll tell you but, if you just wanna answer that question, fine. I mean I’m not ashamed I’m wearing this”.

The opportunity to talk to specific others and more general others fulfills different needs and has various meanings for Jane’s self and identity.

4.3.5.2 Narrative forces

The existence of multiple narratives was both liberating and limiting depending on whether they were integrated to develop a whole, or conflicted with each other. Jane’s location in certain narratives, and her lack of ability to seek out alternate narratives were restricting forces.

The public narratives that Jane used to describe her first few years of living with diabetes conveyed a sense of imposed confining narratives. The family, medical and social narratives which all defined diabetes as a stigma framed Jane’s self and identity. The fact that she did not have narratives with which to positively identify resulted in feelings of confusion, powerlessness, and victimization.

The existence of conflicting narratives was also apparent in Jane’s first few years of living with diabetes. On one hand, she was treated like a “porcelain doll”, and had to adopt new, difficult behaviours. Thus she was positioned within the diabetes narrative. Yet, on the

other hand, she was pressured to “hush up” this part of her. Jane was caught between conflicting narratives; she was treated differently but was not allowed to talk about this stigmatizing attribute. Jane felt angry and depressed during this time. “It was a constant thing, I thought about it quite a bit...and I really didn’t quite cope with it, it was kind of was there, but not there. I thought about it, it was depressing”. Her reference to diabetes being there, but not there, demonstrated this ambivalent and fleeting recognition of identity.

Part of Jane’s process of incorporating diabetes into her self and identity, and learning to balance its demands, was an ability to develop an alternate diabetes narrative, and also to balance the diabetes narrative within the context of other existing narratives in her life. Jane said that she achieved “some sort of integration where it’s now like a wheel with the spokes, and everything fits in. And it’s all part of it, and it becomes part of the routine....now there’s some sort of sturdiness and something holding it together....the fact that you have it, you’re holding down a job, you’re living in your own place, you’re able to cook clean whatever, do it you’re able to do things you’re on the go...getting involved in student counsel, going to school part time...busy socially”. It seems as if Jane succeeded in developing a comfortable ontological narrative within the public narratives of school, career, social structures, etc. The language that Jane used in her narratives conveyed changed meanings about her diabetes identity. Jane viewed diabetes as a “condition”, not a “disease”. “Now, when you say condition, it implies you have something, but at the same time you can live...it doesn’t cripple you, it becomes part of your life”.

Despite Jane’s comfort with her self and her identity at that time, there still loomed the threat of conflicting and destructive narratives and thus a problematic identity. Jane talked

about a fire, “once you get a fire going and it’s blazing, and then when the flames cool down, you still got hot ashes. Now you gotta be very careful, cause the hot ashes can erupt...occasionally you get another fire roaring again...so you gotta be careful”. Jane’s identities continued to be fleeting and ambiguous and the confidence of integration was never assured.

There was an ambiguous character apparent in the various dimensions of Jane’s narratives. Jane was continuously managing her narratives in order to achieve balance within her self and her identity, but there were always changes occurring which were part of the continuous renegotiation of Jane’s selves and identities.

4.4 Barb

4.4.1 Summary of Barb's experiences with diabetes

Barb was diagnosed with diabetes at age 5, and had been living with diabetes for twenty years. As a child, her mother managed her diabetes. Barb had difficulties dealing with her diabetes because it affected her social interactions with other children. At camp, she felt that there were “normal” children and “diabetic” children, because they were separated at meal times. At school, her mother asked her teachers to not tell the other children about Barb’s diabetes, but it inevitably became known, and Barb was teased by the children. Barb said that she “cheated” when she was a child, and had difficulties with the diabetes regimen.

At age 14, Barb went to a psychiatrist who helped her deal with the diabetes and to recognize that she was not “different” just because she had diabetes. She became more comfortable with her diabetes and devoted time and energy to managing her health. When she went to college, she took responsibility for her diabetes and her body, and also began to test her limits and to experiment with her diabetes. She took a theater course and travelled in Europe, and realized that she could balance both her interests and her diabetes.

Growing up, Barb felt that she had to be a “perfect diabetic”, which she felt was expected of her by health professionals. She said that health professionals eventually changed their position, moderating their approach to diabetes management, since they recognized people with diabetes as “human beings”. Despite this change, Barb still felt guilty when she did not achieve good control, because of the messages that she had previously received.

Barb prioritized her health, and thought about her diabetes constantly, but she felt frustrated over her lack of control and the continuous “guesswork” required. She tried to

adapt her diabetes management to her work responsibilities and to social events, but she was not always successful at balancing her diet, exercise, and insulin. On one hand Barb felt that she had become more in tune with her body but on the other hand, she felt as if she did not trust her body because she could not anticipate how it would react and could not always determine when she was having a reaction. The frustration that she felt and the constant care her body required contributed to anger and depression.

Barb had various support systems. She valued her physician and described him as extremely supportive and reassuring. Barb began a support group for people with diabetes and she found the meetings very helpful because she no longer felt alone. Barb did have difficulties dealing with the general public because they were not educated about diabetes and did not appreciate the demands of living with diabetes.

Barb recognized that diabetes is a part of her self, but she was constantly struggling with how to balance her various priorities in life.

4.4.2 Narrative identity

Barb's narrative identity challenged the notion that an individual's identity is disrupted and reconstructed following the diagnosis of a chronic illness. Since Barb had been living with diabetes from the age of five years, the notion of disruption was not appropriate. Barb's narrative demonstrated that identity formation, and the integration of diabetes into this identity, is a continuous process, and responds to and influences other aspects of her identity.

At the age of 25, Barb interpreted her childhood identity as having been strongly influenced by the public narrative of chronic illness and stigma. Discourses about who or

what is valued were recognized and enacted at a young age. Others' recognition of Barb as a 'diabetic' overshadowed other aspects of her identity. Barb described feeling different compared to "normal" children, which contributed to efforts to hide her self. "Everybody else sort of sat wherever they wanted to, so it was sort of like the diabetics were here, and the normal ones were here. So that's sort of for me where that term [normal] comes from....just because of diet". "Kids don't understand. You know they are the cruelest. Very much so, and I was teased about it".

As Barb matured into adolescence and then entered college, she was motivated to challenge this public narrative of stigma instead of being forced to operate within it. Barb had been able to change her recognition of her identity and wanted to change others' recognitions. Barb attempted to change cultural diabetes narratives by constantly challenging society's lack of education regarding diabetes. Through various efforts, Barb claimed that she was no longer ashamed of the diabetes, that it was a part of her. "I'm not ashamed of it...and I don't go out of my way to tell people, but I figure if they're going to get to know me, that's part of me". Barb had to balance her need to counter stigma narratives with her need to protect her own interests. The ontological narratives that Barb was able to construct were shaped within the limitations of public narratives. About her decision to not put diabetic on her driver's license or on job applications, Barb said, "until people are more aware of what diabetes is all about...and have a really good understanding of it, I'm not putting myself out".

Barb was part of changing medical narratives throughout her experiences with diabetes, all of which shaped her identity with diabetes. "They finally have taken a look at us as human beings and not as this machine that is programmed to do exactly, to be perfect. And

you know, so that was really super...I mean we're not perfect. And for a long time we were told we had to be, and it's impossible. And they helped us to live with it, you know, that's the biggest thing, is they've taken the time to look at all of these things and say okay now you know, what can we do to change things so that people can live with it. As normal as possible". Despite this changed narrative, Barb still felt caught up in the "do's and don't's", and felt guilty if she did not succeed with her management. This demonstrated the extent of her identification with entrenched medical narratives and how much her identity and self were caught up with their definitions.

Barb struggled to balance her various identity desires and needed others' recognitions to help her. Significant others helped Barb develop her own comfort with her diabetes identity. Her physician was particularly supportive in affirming her diabetes narratives, "He [doctor] has the attitude, like he makes you feel like you've got all the time in the world. And that really is important. I guess, a lot for me, because I need a lot of reassurance about my diabetes". Barb succeeded in developing her diabetes narrative through the support of other people living with diabetes. Barb was involved in the organization of a support group for people with diabetes, which was very valuable for her. These meetings provided the opportunity that at defined times and places, and with certain people, Barb was able to focus on her identity founded on diabetes. "The biggest thing is just sharing experiences with people....sitting down with people who understand what you're going through....I guess it's just the support that I can get, from the group, and knowing that you know we've all gone through exactly the same thing".

Barb's health and illness narratives were also connected with public narratives of

individual independence. Barb had a need to be independent, to not allow others to help her when she was experiencing a reaction. She needed to be responsible for herself and to maintain control. The themes of control, responsibility, and independence permeated her narratives of diabetes.

Family and social narratives, especially those representative of Barb's lifestyle, also significantly affected Barb's diabetes narratives. Barb's family narrative revolved around her mother's behavioural expectations, "my mother hasn't said it, but I know in the back of her mind she's saying, you shouldn't be doing that". The family narrative was countered by her friends' narrative which involved Barb's social needs and her relations with her boyfriend.

Barb's narratives demonstrated a continuous development of identity which was contingent on her specific needs, her relations with others, the place, and time. Barb used various narratives to help her understand her past experiences and to construct her present desired identity.

4.4.3 Self

Barb's reflexivity and subjectivity concerning her cognitive and physical self was observed through her narratives about the chronicity of diabetes and its interpretation in relation to her self.

As a child, Barb was teased about her diabetes. Barb was very sensitive about having diabetes and compared herself to "normal" children. Barb said that because of the diabetes she was an introverted child. During her childhood, Barb negatively perceived others' and her own identifications of the stigmatization of diabetes, which contributed to her feeling

uncertain about her self. As Barb grew older and received help from a psychiatrist, she emerged from her shell. She reflected upon and shaped her self according to her own needs, which in turn influenced how she presented herself publicly. Despite Barb's increased comfort with her diabetes, she continued to reflect on her self and to compare herself to others who do not have diabetes. "I guess I do draw comparisons between myself and other people...like I feel sheltered a lot of the time, it's like okay I can do this and this and this, but no I can't do that. Whereas everybody else can do that". The constant processes of subjectivity and reflexivity that diabetes demanded made diabetes a challenging condition.

Barb's subjective reflection on who she was, how she managed the diabetes, and the meaning of her self in relation to the diabetes, contributed to a range of feelings experienced during the twenty years of living with diabetes. These feelings represent the complex cognitive process of the self. Barb described feelings of anger, guilt, depression, and frustration, which were always with her. She said that "it's very hard to be a diabetic". "Angry, you get really teed off. You know, you get depressed...there's such a wide range of feelings that go with it. A lot of times its anger. Because of the unpredictability. And depression".

Barb stated that there was never a point of acceptance of diabetes. This expression reflected the constant struggles which occur within the self when dealing with a chronic illness like diabetes. "You do go through a lot of guilt...and I've tried to deal with that, I've tried to work on that, and it's very hard....it's been drilled into me so much, the do's and the don't's. Um, that even when you say you can do this and I've been told in the past you can't, it's like the guilt comes back. And, I don't know if I'll ever get rid of guilt. Um, I hope so, you know

I'd like to eventually".

The constant presence and demands of the physical self, and the interconnectedness of the cognitive and physical selves was demonstrated with these words. "It goes with you everywhere you go. And, it gets very frustrating, you know you really, you get to the point where you just wanna say screw it. You know, I've had enough. I mean I look forward to going to bed some nights, because it's like, it shuts off....maybe it's just me...I am very attuned to it".

Barb had been living with diabetes for 20 years, and thus her self had been connected with the diabetes narrative for the majority of her life. The emotional effects of diabetes on the self, and the continuous evaluation of the self in relation to the diabetes was communicated through Barb's narratives.

4.4.4 Body

Barb's diabetes narrative was largely focused around the experiential bodily aspect of living with diabetes. Diabetes was interpreted by Barb as a bodily condition which was integrally linked to her self and identity. Barb's narratives illustrate various meanings that Barb has attached to her body, which have implications on her different selves and identities.

Barb's mother cared for Barb's diabetes when she was a child. The fact that Barb's mother assumed responsibility for her body meant that Barb did not have to tune into bodily meanings. As Barb matured into adolescence, she took control of the diabetes and her body. This change of responsibility contributed to an opportunity for Barb to connect her self and her body, and to increased comfort within social processes. This initiated a process of

learning to read her body. Barb explained that this increased competence in managing her body led to increased confidence managing the diabetes. "When I was a child, it was like, I wasn't really responsible for it. You know, like yes I took my needle every day, I ate what I was told to eat. But at the same time it was like, she was looking after it. So whereas now, I mean I know myself and I know what my body can do, and how it reacts in different situations. So it's like, now I can sort of go into different situations a little more relaxed than I used to".

Having diabetes forced Barb to develop a unique relationship with her body; her body had tremendous meaning for her because of her belief of the interconnectedness between her body and her self and identity. Barb believed that everything affected her body, such as stress, and thus she gave her body tremendous attention, and was very sensitive to changes in her body. Barb said that she "plays with things" to learn her body needs. "You get to know your skin and your body pretty good, when you've had it for a long time....you do become very sensitive to what goes on in your body. Because you deal with, you're constantly dealing with any sort of changes that happen".

Despite the tremendous time and energy that Barb spent caring for her body, there was a feeling of antagonism between her self and her body. These feelings resulted from the condition that biologic requirements for existence intervene in everyday life. Barb's efforts to unite her body, self, and identity, and to maintain control for social and physical purposes was challenged by her body's unpredictability, which led to feelings of anger, guilt, and depression. Barb explained that caring for her body is constant "guesswork" and involved juggling the many contributing factors that affected her diabetes. The lack of control and the lack of

predictability led Barb to feel a lack of trust of her body, that she could not depend on her body. "It's frustrating because you have to juggle everything...you try and do your best and you hope that you know one day will hit on. But it's guesswork every day....you look at your diet, you look at your insulin, you look at your exercise. But you don't look at the other little tiny things...and that gets frustrating you know because it's like, you want to do the best you can. And then, when you don't get the results that you wanna get, you start, well for myself I feel guilty. It's a never ending cycle". "It's an insecurity of, at times you don't trust your body...occasionally having a reaction and not being able to tell that you are".

Barb's concern with her body stemmed from health and social needs. Barb's identity could not be separated from her embodiment within social situations, and thus body management during these times was critical. "When you're in a crowded situation, and you don't know the people, and it's like, you know, all of a sudden I'll start getting shaky, that kind of thing. I get embarrassed, it's like I can't explain to this group of people what's going on with me, and I don't know what's going through their head at that moment when they look at me". "I don't like letting people know I'm having a reaction, like I prefer that, you know, if I can handle it myself I prefer they don't know".

The many experiences that Barb had with her body contributed to an understanding of her body as different compared to the bodies of others who did not have diabetes. This belief represents the tremendous meaning of the physical body in relation to the self, the role of the body in differentiating one's self from others, and also how the body with diabetes dissociates from others. "You have a different perspective like, you know, I don't get up in the morning and think okay I'm having a bowl of cereal, I'm having my carbohydrate, which is going to

get me to work...and it's not like I'm eating a donut, it's like I'm eating sugar, too much....I mean my whole life has been like that". "It's frustrating, because, you know, like anything that a normal person gets is twice as bad for me, because it screws up the diabetes....like a cold to you is nothing. I mean you feel miserable and that kind of thing, but a cold to me, my diabetes goes completely out of whack. Any sort of infection...and so you become more sensitive to any changes in your body".

The centrality of the physical body to Barb's self and her degree of body-relatedness was further illustrated in her comments about the implications of her body on her future and her concern for her body. "A lot of times I don't really think ahead, basically all I think about is today. You know because I, I mean I don't know what's gonna be down the road 5 years from now, you know, I've been told that eventually my kidneys may go, and it's like I can't think about that right now. Um, cause I would go crazy". "The one thing I don't do is, is sort of put it back on the shelf and try and forget about it, you know, because it is something that's very important to me, it's something that for my well being I have to consider all the time".

The various meanings of the body conveyed through Barb's narratives demonstrate the interconnectedness between the body, self, and identity.

4.4.5 Narrative

4.4.5.1 The process of storytelling

Barb's interview narrative provided her with the opportunity to plot the different phases of her living with diabetes through her childhood, adolescence, and into young adulthood. Through these narratives, Barb constructed her own understanding of her self and

identity in the past and present. Her changing stories and thus self and identity reflected the changing positioning within narratives which involved different relations, times, and places.

The ability to talk about diabetes with others was an important theme throughout Barb's diabetes narrative. The process of storytelling allowed Barb to make sense of diabetes for herself and others, which helped in her understanding of her self and identity and her relations with others. Barb identified her interaction with a psychiatrist at the age of 14 as a critical turning point in helping her to deal with her diabetes. This was an opportunity for Barb to verbalize her stories, to make sense of the diabetes, and to develop an alternate diabetes narrative that coincided with her desired identity. "I went to see a psychiatrist to try and help me deal with that. Um, because I would never go out of the house, and it was because of the way I had been treated as I was growing up. And that, you know that helped me a great deal. To see that I'm not so different from anybody else just because my pancreas doesn't work. Or because I have to take a needle".

Barb said that she did not tell anybody about her diabetes when she was growing up until college at which time she began to share this part of her self with others. The ability to talk about her diabetes was a key aspect of Barb's increased comfort with managing her body and her diabetes, overcoming the stigma of diabetes, and affirming her sense of self and her desired identity. Barb said that as long as she can explain her diabetes and her needs to others then she is comfortable with her diabetes in relation to others. Explaining her story and positioning her self within these narratives allowed Barb control over her identity.

As Barb matured, she verbalized her stories and constructed new narratives. This raises the question of the relationship between age, environment, and the ability to construct

narratives, and whether we have greater opportunities to challenge discourses as we develop more confidence and knowledge. If so, then this might demonstrate the need to make the environment optimal for children and teens to develop their own strength and confidence to tell stories when this might be seen as a difficult challenge.

Barb's physician was also integral to her storytelling. Barb was grateful that her physician listened to her "ranting and raving". Barb explained that she needed to be able to share her stories with her physician because it helped her to make sense of what was happening to her. "Just to have somebody sit there and listen to you. And listen to all your ranting and raving, and that kind of thing and just to be able to sit there and cry, and to be able to get what you're feeling out".

This need to talk about one's self in order to provide a sense of coherence and clarification to one's experiences was also demonstrated by the value that Barb attached to belonging to a support group for people with diabetes. "The biggest thing is just sharing experiences with people....sitting down with people who understand what you're going through".

4.4.5.2 Narrative forces

Barb's research narrative demonstrated the importance of having the opportunity to seek out alternative narratives. Through this process, Barb constructed a desired identity. The exploration of various narratives was a positive achievement for Barb and allowed her to overcome the control of diabetes on her self and identity. By travelling, and pursuing her interests and studies, she was able to develop an identity based on multiple narratives that

could be integrated together. "I'm tired of doing it, you know I'm tired of compensating all the time or not doing things because of diabetes because for a lot of years, I never did. For a lot of years I was very...home a lot of times like, you know I was always in bed by you know 9:00 so that I got my proper rest and all of that, and then finally it just came to the point where I guess when I went to college. I finally said that's it, you know I have to see what my limitations are".

These multiple narratives were not always successfully integrated and when they conflicted, the resulting pressure and frustration resulted in a confusing and fragmented identity. Barb felt pressured between socially defined discourses of diabetes management and optimal health care practices, and the discourses of social and personal development and relations. Barb experienced anxiety and guilt from living amongst these conflicting discourses, the extent of which varied depending on the particular time. "Sacrifices now that I have to make are not that great. As it was compared to the past. I used to get a little angry at it, you know, like I think that goes through everybody, like why me....and you sort of come to terms with that as well". "I weigh every situation as to how it's gonna affect my health. So, you know I'm probably the opposite end of it, it's like maybe I think about it too much". "Part of me is saying, you know I don't care, you know, and I'm going out tomorrow night and I'm going out Saturday night, I'm going out Sunday and I don't care. The other part of me is saying, no that's really dumb.

The availability of multiple narratives and the ability to pursue these paths was rewarding, but being caught within their contradictions was a constant challenge.

5. DISCUSSION

The analysis was presented according to each respondent because each respondent's experiences with diabetes were unique and illustrated the meaning of living with diabetes in a different manner. Despite the differences, common processes and themes were apparent, some of which will be discussed. The discussion has been divided into narrative, self and identity, and the body. This study has focused both on the theory of self, identity, body, and narrative, and the integration of this theory with respondents' stories of their daily living with diabetes.

5.1 Narrative

During analysis, two major levels of narrative emerged, the research narrative which was the product of the interview, and the content and process of narrative found within the research narrative. Each level of narrative provided important insight into the experiences of diabetes within the context of self, identity, and the body. General issues related to the understanding of social life as storied arose.

5.1.1 Research narrative

The research narrative represented participants' positions at a certain time and place, and in relation to the interviewer, and thus the findings must be viewed within this framework. Although the specifics change with time, the processes involved and the ideas found enhance our understanding of living with diabetes. The research narrative could be understood from two angles of analysis, the structure and the content of the narratives.

An exploration of the structural elements of the stories told by the respondents was a window into an understanding of their experiences. The structural elements used as tools of analysis in this study confirmed Somers' (1994) and Connelly and Clandinin's (1990) descriptions of narrative components. These included place, context, temporality, emplotment, relationality of parts and selective appropriation. Although the transcripts were not coded according to these elements, the continuous thought and attention given to these elements and processes contributed to an understanding of the positioning of the participants within the experience of diabetes. While this tool was used in a research framework, an understanding of this process can help both health professionals and friends and family of individuals with diabetes understand how individuals make sense of their experience of diabetes and what forces shape this process.

The structural analysis was a means of positioning and exploring the content of the interviews, which differed for each individual. What was talked about, what was emphasized, how events were interpreted, the particular others discussed, how issues were positioned, and how the past, present, and future were discussed, were some of the specifics which provided insight into each individual's experiences with diabetes. While all participants talked about their bodies or the stigma of diabetes, the way that these issues were discussed, and how it changed over time, was specific for each individual and demonstrated what was important and representative of each respondent's experience. This demonstrates the individual meaning of diabetes, and the need to listen to individuals and to provide them with the opportunity to "reclaim" their illness, as Frank (1995) said.

It is important to remember that the respondents were interpreting their past from their

present position. The structure and content of their narratives were shaped according to their angle of interpretation at the time of the interview. As Gadamer claimed, experience and story are in dialogue with each other and this interaction results in the development of new meanings and in the creation of identity (Widdershoven, 1993). The changing character of the narratives presented will hopefully also convey that the results found are a certain snapshot representative of a certain desired identity at a specific time, and the stories and identities will continue to change over time.

5.1.2 Narratives within the research interview

Within the research narrative, narratives and respondents' selves and identities existed in a mutually constitutive dynamic. Within this dynamic, unique for each individual, the experience of diabetes was made meaningful. Although the specific experiences were different for each individual, there were common processes representative of this interaction.

The ability and opportunity to talk about one's self and diabetes was a common issue. Who was talked to, and what was talked about, fulfilled different needs and had different meanings for respondents' selves and identities. The stigma of diabetes affected all of the respondents' experiences talking with others. This sharing involved both strangers and friends, and the particular responses had different meanings to the respondents, depending on who the other was and how they wanted to be responded to. Comfort talking about one's self and diabetes reflected an ability to have others attach the diabetes to one's identity.

The need to talk about one's self and diabetes represented an essential process of interpreting what one was experiencing and feeling. For Pat, Jane, and Barb, the need to

verbalize one's self required a certain other to act as a witness, such as a physician, and a context that allowed for this exploration and construction. The act of talking or not talking about one's self and diabetes was representative of the respondent's relationship with diabetes. The changing nature of these stories characterized the changing of that relationship. Frank's (1995) suggestion that telling stories reaffirms relationships with the self and with others was also confirmed in this study. Sue did not present this same need for storytelling within her interview narrative, yet Sue had also not achieved a comfort with having diabetes as the others had. The contrast between Sue and the other three women was probably due to numerous factors, such as the interview situation and the duration of living with diabetes, and it is possible that the value of storytelling to this process is amongst these factors.

A significant image that emerged from the analysis was the positioning of respondents within a myriad of narratives, and the changing of these narratives, and respondents' locations within them, that occurred over time in response to various forces and conditions. Thus the experience of diabetes has to be understood as occurring within these multifaceted and changing constructions. The existence of conflict and prioritization amongst narratives, in combination with personal experiences, were some of the conditions which shaped and changed the participant's ontological and public narratives and their position within these. Pat's stages of 'crash', 'integration', but always being in a 'big tangle', and Jane's stages of 'rampages', 'integration', but 'threat of eruption' demonstrated this continuous and precarious positioning. Sue's narratives differed, which seemed to reflect a holding onto the narratives in which she was located and a resistance to existing within new and different narratives. It is difficult to make a conclusion concerning the role of narratives in contributing

to different experiences with diabetes, but it is an idea which is worth pursuing with a larger sample size.

Respondents' experiences with diabetes can be understood as existing within the process of telling stories and the existence within multilayered, varying, narratives.

5.1.3 General issues about narrative

Various questions and ideas about narratives arose through the analysis of the participants' transcripts which have implications for the experience of diabetes and for the broader notion of social lives being shaped by narratives. These questions are concerned with the power, or lack of, to shape, seek out, identify with, or resist narratives.

How are narratives constructed? Through this study, it was recognized that various levels of construction were identified, although these levels are not easily separated. Somers (1994) explained that existing narratives are determined by historical and cultural forces and by the distribution of power. It was beyond the scope of this study to explore structural forces, but it is understood that it is important to recognize the role of broader determinants, which include political, economic, and social power, in the construction of narratives. The social and individual levels of narrative were apparent. For example, family narratives had a significant influence on the respondents' experiences with diabetes, as did narratives that developed through interactions with friends, physicians, and workers.

The individual level of narrative construction was shaped by the other levels of narrative. The respondents demonstrated different approaches to adopting these narratives which raises questions about individuals' abilities to construct or to choose, depending on the

situation, their own narratives. Through examples from the respondents' experiences, different elements of the process were apparent. Feeling caught in narratives that one does not want to be within, ambivalence over which narratives to identify with and which to resist, pressure to identify with narratives which are socially valued, frustration with the lack of available narratives, and having the opportunity to seek out different narratives, were all apparent in the participants' experiences. These features of the process of narrative were shaped by the individual, her social interactions, and wider social processes. Due to the small sample size, it is only possible to question how duration of diabetes, age of diagnosis, and gender, might influence the type of narratives told. It is important to be aware of the power of narratives and how they could be both empowering and limiting depending on the context.

This discussion about narrative and diabetes has emphasized narrativity in order to position the context within which diabetes was occurring. An understanding of the process elements is essential to an appreciation of the context within which individuals live with diabetes.

5.2 Diabetes, self, and identity

The theoretical framework of identity, self, and narrative, produced an important perspective of the everyday context of living with diabetes.

Somers' (1994) concept, narrative identity, involves the dimensions of time, space, and relationality. This definition was exemplified through the participants' experiences. The participants had many identities over periods of time and also within specific time frames, in relation to different people and in different places. For example, the participants' particular

location, such as home, school, and own apartment, their relations with others, such as physicians, parents, friends, strangers, and the particular time of their life or even day, affected their location within ontological and public narratives which in turn shaped their identities with diabetes.

The fluid, contingent, and contextual character of identity positions the meaning of diabetes within a web of multilayered narratives. Diabetes is not merely a matter of behavioural changes, but it has tremendous meaning to an individual because its narrative interacts with the many other narratives which shape and in turn are shaped by an individual's identity. This approach to identity exemplifies that individuals are not 'diabetics', and that having diabetes is only one narrative existing amongst many other narratives.

Calhoun's (1995) discussion about recognition was also exemplified through the participants' experiences. As Calhoun stated, recognition is vital for identity construction which is a vital aspect of subjectivity. Being recognized a certain way which affirmed or denied the participants' desired identities, or not receiving appropriate recognition, had significant influence on the participants' feelings of self and their interactions with others. Recognition by peers at various lifestages, by parents, physicians, diabetes support groups, and strangers, were all significant 'others', in addition to the self, that shaped the experience of diabetes.

Calhoun's (1995) emphasis on the existence of tensions amongst discourses and the resulting difficulties in achieving social recognition and a coherent subjectivity, was also confirmed by the participants. The narrative of diabetes conflicted with other public narratives which shaped the participants' lives. For example, the stigma of diabetes, the

conflict of diabetes with desired self presentation, the conflict between diabetes and social needs, were only some of the tensions which the participants experienced. These tensions led to difficulties managing identities in social interactions, and also to difficulties in achieving a coherent sense of self. Living with diabetes in our society means living within discourses which could contribute to torn and fragmented identities.

The importance of differentiating between the self and identity was observed through the analysis conducted. Diabetes was interpreted and managed differently in relation to one's identity as a social, shared process, and to one's self as a reflexive, subjective construct. It is important to recognize these two processes which are operating in order to gain a comprehensive perspective of an individual's experience with diabetes. Pat's self destructive period following her crash was a struggle of her self. She said that others did not know what she was doing to herself, and thus was managing a certain identity separate from the self. Sue was attempting to manage an identity based on independence, education, and control, but her self was experiencing feelings of anger, fear, and vulnerability. The self might be a more difficult construct to study because it is characterized by a reflexivity of the individual and some individuals might be better than others at expressing this process, whereas one's identity as a social process might be more readily observed. Through the participants' narratives, it was possible to identify how the management of one's identity influenced the construction of the self, and also how the needs of the self influenced one's identity presentation. The direction of influence changed depending on the context, the participant's needs, and the influence of others.

5.3 Diabetes and the body

The particular questions asked of individuals about their bodies will influence the type of stories received. As Turner (1992) suggested, there are different approaches to studying the body, and each addresses different questions. The goal of the interviews for the present study did not include a specific orientation to the study of the body, but due to the centrality of the body to the experiences of the participants, issues of the body were central to the discussion and the analysis. A significant portion of the analysis of the body focused on the phenomenology of embodiment, the body as a lived experience. Turner's claim that it is necessary to recognize chronic illness as an incursion into one's embodied self hood was exemplified by the experiences of the respondents. Although the emphasis was on the lived experiential body, examples of the body as an objective, institutionalized body, were also observed.

This study demonstrated the necessity of the study of the body within the context of a chronic illness. The body was the location where self, identity, and diabetes were connected and made meaningful in terms of the physicality of the individual. As Kelly and Field (1996) suggested, the participants' bodies were connected to their selves and to their identities. For example, their experiences and feelings associated with the illness, such as feelings of guilt, anger, and frustration were representative of the self, and managing the diabetes within social processes, such as their efforts to maintain high blood sugars when in the company of certain others, was connected with their identities. The participants' experiences of struggling with their bodies, selves, and identities as they were prior to the diagnosis and within the changes demanded of diabetes, confirmed Kelly and Field's claim that in the experience of illness, there

is a tension between continuity and change amongst the body, self, and identity.

Turner's (1992) discussion of the phenomenology of embodiment, of the interconnection between organic systems, social processes, and cultural frameworks, was repeatedly observed in the participants' narratives about diabetes. The participants' experiences with diabetes were made meaningful through their bodily feelings and the physical and emotional changes which occurred to their bodies. Their changed relationships with their bodies influenced and were also influenced by their interpretation of diabetes. The experiences of working against their bodies and being in tune with their bodies represented various types of positioning of their selves and bodies within social processes. Efforts to control the body, to use the body as a means of communication of one's self, or to represent the body in a certain way, were all geared to operating one's identity within cultural expectations and social processes. The respondents varied along Frank's (1995) continuum of body relatedness, being associated with one's body versus a state of dissociation, and the continuum of other relatedness, an individual's relationship, as a body, to other people who are also bodies, depending on their particular location within ontological and public narratives. The emphasis by the participants on the need for control and frustrations over lack of control, confirmed Turner's claim that identities of individuals cannot be separated from their embodiment within the interactional situation.

The body as a symbol of social construction of power and knowledge was observed through the participants' emphasis on the value of control and compliance. This finding is similar to that of Olesen et al. (1990) who found that the physical self of individuals is a product of societal and cultural themes. Thus the desire for independence, valuing one's self

according to adherence to the diabetes regiment, and frustrations over lack of control, represent spheres of knowledge that have been constructed and valued in our social and cultural context. Resistance to this power was observed through participants' acting out through their bodies.

Although the concepts of control and independence could be positioned within this social constructionist argument, it is important to recognize that a balance needs to be achieved between the multilayered meanings of control and independence. The biologic realities of diabetes do demand a focus on elements of control and self care, and these concepts cannot be critiqued as being social constructions of power and knowledge, without recognizing the biological necessities of the condition. Individuals need to find their own comfortable position on Frank's (1995) body problem continuum of control, which involves predictability of the body versus a contingency, being susceptible to uncontrollable forces.

The body is a fascinating area of exploration because of the many ways of interpreting its various meanings, and it is difficult to capture its complexity. For example, Charmaz (1995) talked about individuals' struggles against their illness, whereby their bodies were objectified and distanced, and a progression into a struggle with illness, whereby bodily facts were integrated into their self concepts and lives. From the present analysis, it was demonstrated that struggling 'against' and 'with' bodies is simultaneously occurring because of the nature of the condition, although one approach might dominate at certain times.

Saltonstall's (1993) study with healthy young adults found that the body and self were described as reflexive aspects of one wholeness. It could be asked whether this notion would apply to the respondents in this study. It is important to question the meaning of wholeness.

Despite the experience of problems with their bodies, and feeling as if their bodies were working against them, I would suggest that the concept of wholeness does apply to these participants with diabetes. The fact that the body was a constant part of their diabetes narratives, and contributed to many feelings such as anger and frustration, demonstrated that their physicality could not be separated from their selves. These difficult interactions and tensions between different aspects of the self is captured by Petrunik and Shearing (1988) in their description of the “I”, the “Me” and the “It”. As discussed by the women in this study, their bodies were often viewed as foreign entities, the “It”, which was in conflict with and could overcome their “I”, their source of action. Although the diabetes was at times conceptualized as an “It”, the body could not be separated from the “I” and the “Me”. The physical challenges of diabetes demand a reinterpretation of the relationship between the self and body, but these physical demands reinforce the wholeness and interconnectedness of the body and self.

5.4 Conclusion

Little of the work in the sociology of chronic illness has concentrated on diabetes. The results from this study demonstrate that similar processes or themes might exist within the experience of chronic illnesses, but the study also signified the importance of recognizing the different meanings of different chronic illnesses. The physiological basis of diabetes, the daily management, the young age of occurrence, and the constancy of the condition, contribute to unique experiences. Although the sample size of this study is small, it is hoped that validity and authenticity were achieved by presenting the women’s detailed experiences in

conjunction with theoretical explanations. While the transferability potential is limited, it is hoped that the meaningfulness of this study will build upon previous work in the sociology of chronic illness, in particular diabetes, and will contribute to future studies.

In addition to understanding the specifics of diabetes within the larger umbrella of chronic illness, this study also integrated recent theoretical ideas about self, identity, the body, and narrative into an understanding of living with diabetes, which previous interpretations of this data, and other qualitative research in the area of diabetes, have not addressed. The need to continuously reflect upon and integrate theoretical perspectives was apparent. Through an analysis and incorporation of recent theory, the experience of diabetes was positioned in a different way, which added insight into the meaning of living with diabetes the implications of which will be discussed.

This study has illustrated that living with diabetes must be understood within the complex processes of identity, self, the body, and narrative. While the biomedical perspective of diabetes is essential, it must be integrated with a sociological understanding of the way that the experience of diabetes is constructed and lived on a daily basis. Diabetes must be interpreted within this multilayered system of narrative construction, and it must be remembered that diabetes is only one aspect, existing amongst many others, of this complex system. There is a tendency in our social world to order and categorize, as demonstrated in previous research in the area of chronic illness, identity and self. This study illuminates the ambiguity and blurring that occurs by emphasizing the contradictions, dilemmas, continuous change, and multiple forces, which shape the construction and interpretation of the experience of diabetes.

5.5 Implications

This study utilized various theoretical frameworks as a means of exploring the experience of diabetes. I will now propose some ideas addressing how these findings can illuminate the everyday medical and social contexts within which diabetes is lived. I believe that the findings have implications for those living with diabetes, for health professionals, and for people who have close relationships or merely come into passing contact with individuals who have diabetes. Valuing the individual process of storytelling, recognizing the social responsibility of 'others', and providing the wider picture within which diabetes management behaviours occur, are all important issues which arise from this study.

The findings of this study demonstrated the role of storytelling in both medical and social contexts. Storytelling helps interpret events and provides coherence to experiences. Through this creation of meaning, identities are developed. By recognizing this integral function of storytelling, health professionals and friends and family of individuals with diabetes can provide the opportunity for this process to occur. Individuals' stories and how they talk about diabetes can provide insight for others to understand their experiences and struggles with diabetes. Health professionals can listen to how individuals talk about their bodies, or friends' and families' understandings of why individuals might have difficulties discussing their diabetes, can help all involved to better appreciate the challenges to and ways of living with diabetes.

Individuals need others to listen to their stories and to provide them with appropriate recognition. An important theme which emerged during the current analysis was the integral role of others. We all have the responsibility, as Frank (1995) says, to be "witnesses".

Whatever our particular relationship to the individual with diabetes might be, such as partner or nurse or dietitian, we all have the responsibility to listen to individuals' stories because this supports what is being said and affirms relationships. The women in the current study discussed the importance of others' recognitions in attaining a valued self and identity. It is essential to recognize how, as strangers, as close friends, or as health professionals, we influence and help construct others' identities.

Diabetes requires tremendous behavioural changes and individuals are evaluated according to their 'compliance' with the regimen. The current study enlarges our focus from that of an individual's behaviours to a broader understanding of the context within which behaviours occur. Behaviours are not merely done because they are good for one's health. As the women in the current study demonstrated, their behaviours were integrally connected to their desired selves and identities. Furthermore, behaviours are not mechanistic processes whereby the body is separated from the self and controlled according to instructions. By conceptualizing the individual as an embodied self, we can begin to value the meaning of bodily changes and management as an integral aspect of the individual's self and identity. Thus diabetes management actions can be understood according to the location of the individual within relationships and stories with which they identify. By recognizing that individuals' ontological narratives are shaped by public narratives, the personal and social are linked which positions behaviours within a wider framework. The recognition of the role of narratives in shaping individuals' behaviours also allows for an understanding of the tensions and problems which occur with diabetes management because of the existence of multiple narratives and the cultural and historical character of narratives. The dynamic nature of

identity and narrative construction illuminates the behaviour changes that occur over time.

The findings from this study can be used to change the way that we view how experiences with diabetes are constructed. The active role of the individual through storytelling and interactions with others, the role of 'others' in shaping this process, and the multiple forces which shape the personal and social meaning of diabetes could influence the multiple type of interactions involved with individuals with diabetes.

6. A CRITICAL REFLECTION

Research contains assumptions, dilemmas and challenges which should be openly discussed and grappled with. As a researcher, it is essential to engage with and critically reflect on the research process, including the meaning of the research goals and the ways that the research is conducted. This involves decisions concerning the ethics, methods, rigour, and limitations of the endeavour. These issues must be continuously contemplated throughout the research process, from the development of a research idea to the dissemination of research findings. I worked with interview data which were previously collected and transcribed, and this positioned the focus of my critical reflection. I needed to recognize and understand the research stages which I built upon but was not involved with, and contemplate the dilemmas inherent in the interpretation process and the construction of my own research text. A discussion of the issues involved with sampling, interviewing, and interpretation provides the opportunity to express some of these reflexive issues.

6.1 The sampling process

Holstein and Gubrium (1995) cautioned that when choosing respondents it is necessary to ask whose voices will be heard and whose silenced if we conceive of people in certain ways. It is necessary to critically analyze the categories and vocabularies that are used in the identification of potential respondents. How we choose our participants will influence the type of results as well as their transferability potential.

The original sample recruitment for the project 'Living with Diabetes' was conducted through diabetes-related programs at two urban Canadian hospitals, the newsletter of a branch

of the Canadian Diabetes Association, and the Canadian Broadcasting Corporation radio program "Metro Morning". There were various criteria for selection, including the ability to converse in English and a willingness to share personal experiences. An effort was made to select a sample which was representative of both genders and types of diabetes (NIDDM and IDDM), and included a range of ages and duration of diabetes, yet there were limitations with the sampling process. Participation in the study was more accessible to individuals who were active in the health care system and who were willing to talk about themselves. This sampling process raises questions as to whose voices might not have been heard in the study.

Individuals with diabetes who were not accessible through the health care system, those who did not listen to the particular radio station, those who did not speak English, and those who did not have the time, desire, ability, or comfort to talk about themselves, represent some of the groups of individuals with diabetes who were not included in the present study, and who might have different experiences and needs from those sampled.

Four women from the original sample were chosen as a subset for the present study. Despite the common characteristic of being female, the question arises as to who are these women and how do their experiences compare with those of other women? It is important not to generalize women's experiences according to their gender identity. As discussed in this paper, individuals have many selves which constitute their identity, with 'woman' being only one of them. Being a woman might contribute to certain experiences and constructions of health and illness, but other aspects of self also play key roles. The background of the women in this present study is white, middle class. This background provides a certain context for the interpretation of their experiences, which might or might not apply to women with different

education, race, and class backgrounds. Cannon, Higginbotham, and Leung (1988) cautioned that the use of similar homogenous small groups can block the identification of the diversity of human experience. They warn that inattention to race and class as critical dimensions in women's lives can produce biased research samples and result in false conclusions.

The present data consisted of interviews already conducted. Although the sample might be narrow in terms of class and race diversity, this is a limitation which is acknowledged and recognized in terms of the transferability of the results. A focus on young adult women who have lived with diabetes for various durations will hopefully provide insight into certain identity themes which might apply to other women's lives who are experiencing diabetes and similar lifestage experiences and have similar backgrounds. It is possible that the themes and concepts developed through this study might apply to other women with different backgrounds, but further study is necessary to explore this possibility.

The sample size of four is a concern which must be addressed. Qualitative analysis is an intensive, time consuming process which limits the number of participants which could feasibly be analyzed. It is anticipated that the present analysis will have depth and detail that will allow for an understanding of pertinent themes and processes related to identity that are involved in the experience of living with diabetes. It is hoped that the framework and ideas developed will be a building block for further studies that will build upon this foundation.

6.2 The interviewing process

Field texts, including what is told and the meaning of what is told, are shaped by the relationship between the researcher and the participant. The way that an interviewer acts,

questions, and responds in an interview shapes the relationship, and consequently, the responses and reflections on experience provided by the participants (Clandinin and Connelly, 1994). Thus, as researchers, we need to critically reflect on the interview process and how it influences the research findings.

West (1990) discussed the “status and validity” of respondents’ accounts, and the difference between public and private accounts. Public accounts are responses which reproduce the dominant ideology and the “oughts” of behaviours, whereas private accounts may reveal a “deviant” or “darker” side of the situation. West compared Voysey’s study of families with a handicapped child whereby stories of acceptance, lack of disruption, and positive interaction with official agencies was presented, with her own study of families with a child with epilepsy whereby she heard stories of trouble, struggles, and negative interactions with medical care. West advocated the use of triangulation and the need to try to identify the type of accounts that people are producing and the conditions under which they may change. West’s examples nicely represent the different stories that are told, how they are context dependent, and how the way that information is collected is problematic. Qualitative research strives for the ‘personal account’, but whichever account we are hearing, the same questions need to be asked, including why is this particular story told and what is shaping this telling of the story?

Holstein and Gubrium’s (1995) approach, the “active interview”, is a valuable way of positioning the interview and the knowledge gained through this process. They asserted that interpretation is always context dependent, and that active interviewing allows for a more explicit approach to the ways that it manipulates frames of reference for narrative production.

Holstein and Gubrium believe that meaning is socially constituted, all knowledge is created from the action taken to obtain it. Therefore, according to this social constructionist approach, the process, the “hows” of meaning production, which includes the interactional, narrative procedures of knowledge reproduction, are as important as the meanings produced, the “whats”, including the content of the interview.

Holstein and Gubrium (1995) suggested that participants possess a body of knowledge and that their interpretive capabilities must be activated and nurtured in order to provide an environment and framing devices that guide them in the production of knowledge relevant to the particular purpose of the researcher. The participant’s body of knowledge is simultaneously substantive, reflexive, and emergent, and its multifaceted character makes access to it selective and constructive. Thus, in an interview, the respondent is not ‘making it up’, but is constructing a coherent narrative that combines aspects of experience, emotion, opinion, and expectation that are considered relevant to the particular time, place and audience. The role of the interviewer is to activate the narrative production, to offer relevant ways of conceptualizing issues which are shaped by the research topic and by the content of the interview itself. The particular stories told by the participant will depend on the particular identities of that individual that the interviewer chooses to stimulate.

It is possible to take the concepts discussed above and to apply them to the transcripts being used in the present study. I did not conduct the interviews, and therefore was not personally involved in defining and guiding the interviews, which would provide for an experiential understanding of this process. The tapes have been destroyed for reasons of confidentiality and therefore I do not have access to hearing the voices and the ways that

individuals talked. The interviews were transcribed verbatim and I view the data as a type of document. Despite my removed stance, I have a responsibility to study the transcripts for their dependability. I can read the transcripts and speculate how the researchers might have framed the interview context and content. I can also be sensitive to what type of knowledge has been constructed in the interviews and why these particular stories were told, and the limitations of the interview situation.

Each participant participated in a range of two to four interviews. The participants had control over the content of the interviews and were encouraged to discuss their experiences in their own way. Three different interviewers were involved in the interviews of the four participants in the present study (the same interviewer interviewed Sue and Jane). This range of interviewers could be challenged on the basis of the different strategies that would be operating in the collection of participants' stories. On the other hand, if certain common themes are identified despite the different interviewers, this might speak to the significance of these themes. In the present study, the individuals were chosen because of their personal characteristics; who did the interviewing was only later identified. The role of the interviewer always necessitates examination, and the existence of various researchers added another dimension to this process.

I returned to the transcripts to examine the interaction between the interviewer and the participant and to explore whether the interviewers exemplified different styles of asking and responding, and whether I could identify how the interviewer shaped the interview. The interviewer and the context of the interview always shape the interview process and outcome, but I attempted to study this process. Since I could not hear the voices or see the facial

expressions, body language, and physical setting, I am missing integral pieces to understanding the context. Thus, I am only able to study the words on paper.

In reviewing the transcripts, common aspects of the interview process were found despite the different interviewers. Significant differences between the interviewers' styles were not discerned, although some individual characteristics could be identified as influencing the interviews. All of the interviewers used similar approaches to encourage discussion. Responses such as 'yeah, uh huh', were often used to encourage the participant to continue talking without interrupting the flow of talk. Questions such as 'can you tell me more about that?' were used to encourage further exploration or clarification of a certain topic. At times, interviewers repeated what the participant had said in order to clarify their understanding. Differences in interviewers could be identified when the interviewer shared her own personal experiences in order to demonstrate identification with the topic being discussed. For example, one interviewer's husband and another interviewer's brother had diabetes, and thus they shared their stories. One interviewer shared her problems with her body weight. Sometimes responses 'yeah, uh huh' were more commonly used, whereas one interviewer in particular would affirm the respondents' comments with responses that demonstrated a more personal opinionated affirmation of what the respondent had said. Interviewers referred back to ideas raised in previous interviews for further discussion in later interviews, and sometimes referred to the probe sheet at the beginning or end of the interview to encourage a point for further exploration or to ensure no relevant topics had been missed. Interviewers' responses, questions, and probings for clarification shaped the interview, but it is possible to see in the interviews the opportunities for participants to pursue their thoughts and experiences.

There was no order to the interviews which demonstrates an unstructured style, and the different directions and topics of discussion demonstrated the participants' influence over the flow of the interviews. Participants shared their experiences at length. Their ability to continue talking, to raise personally significant issues, and to demonstrate an emotional attachment to their stories points to an environment conducive to the sharing of important experiences. Similar stories and feelings were repeated throughout the interviews by the respondents which might further illustrate the personal relevance of what was shared. An interaction between the interviewer and the participant was definitely identified, and the role of the interviewer in shaping the interview has been acknowledged, but it is also recognized that the participants had the opportunity to openly discuss personally significant issues.

In my readings of the interviews, I was aware of the need to be conscious of the interviewers' questions, framing devices, and ways of asking and responding to respondents' stories. The interviewers activated the diabetes identity of the participants and therefore the stories told were through this perspective, which means that other identity stories, which might have provided further context, were omitted. Since the participants' perspectives were being heard, their comments about family, physicians, etc. were their own interpretations, and we cannot judge others' behaviours solely based on participants' stories because these others might tell a different story if they were interviewed.

How are interviews judged for their 'authenticity' or whether public or private accounts have been shared? It is possible to speculate that a public account of diabetes might be 'compliance' with the diabetes routine and a story about diet, exercise, and insulin. The extent to which the participants talked about their experiences, emotions and opinions to

construct their story, and used past and present relevant resources to shape their narrative, issues which Gubrium and Holstein (1995) discussed, could lead to conclusions about the 'private' nature of these accounts. Even if these accounts were 'private', it is still necessary to ask why are these people saying what they do?

As Benner (1994) claimed, there is an underlying assumption that no one precise story exists, and there are multiple stories shaped by the particular space created by the interview situation. It is important to continuously be conscious of how knowledge is created, how we can know knowledge, and how the interview situation influences this process. This constant attention to the social constructive nature of the text being studied, and it being merely one possible story amongst many, will provide a continuous positioning of the meaning of the research process.

6.3 The interpretation process

I repeatedly asked myself, who am I to interpret these interviews? Do I have a 'right' to impose my analysis on others' stories? What are the implications of the interpretation process? What are the assumptions and limitations of interpretation? These questions, and similar others which I thought about, raise ethical and theoretical issues about the meaning and goals of research.

A humbleness about what knowledge is, how we represent knowledge, and the implications of constructing and using knowledge in certain ways, is necessary throughout the research process. Razak (1993) spoke about the moral and ethical issues inherent in the story-telling process. She cautioned about the need to problematize the limits of our

knowledge. We need to continuously critically reflect on how we hear, how we speak, and the choices that we make about which voice to use. When reading the interviews with women who have diabetes, issues which demand reflection include how respondent's talk about diabetes, how language frames and could potentially limit the description of experiences, how we hear respondents talk, and how we in turn give voice to the experience of diabetes.

Allen and Baber (1992) asserted that our representations are partial truths and descriptions, and we are limited in our ability to fully represent another's experience. This comment puts findings into perspective and positions them as one type of reality. I do not have diabetes, and does one have to know what it is to have diabetes to speak about this experience? Would individuals with diabetes be more successful at representing this experience? Allen and Baber discussed that a challenge in feminist research has been by women of colour who have questioned the motives of white women researching their lives and theorizing about them. The authors suggested that white women should use their advantage to provide time and space so that less privileged women can speak. Can one suggest that the same approach should apply to the study of chronic illness? Am I allowing the voices of those with diabetes to be heard or is my voice dominating in the interpretation? Clandinin and Connelly (1994) spoke to this importance of balancing voices. They suggested that there is a struggle to express one's own voice, while conducting an inquiry whose purpose is to capture participants' experiences and to represent their voices, while also striving to create a research text that will address and reflect upon, the audience's voices. Connelly and Clandinin claimed that it is the researcher's responsibility to discover and construct meaning in the field texts because it is those interpretations which demonstrate the

meaning and significance necessary for social change.

The issue of voice demands an awareness of whose voice is being heard and when, which includes an understanding of the role of the researcher in the interpretation process. It is suggested that researchers need to suspend their beliefs and to 'be open' to respondents' ways of viewing issues relevant to the research project. While it is possible to attempt to delineate the researcher's assumptions, positions, etc., I value Benner's (1994) position that an interpreter can never break away from his/her taken for granted background or position that allows for an interpretative foreground. As Charmaz (1993) said, categories, concepts, and theoretical levels of analysis emerge from the researcher's questions about the data. This idea is positioned against earlier suggestions which posited that concepts were inherent in the data and were awaiting discovery. The questions that I am asking of the data, and my own assumptions and background about health and illness which are shaped by our social discourse, will shape my interpretation of the data.

I need to make an effort to recognize some of my assumptions of which I could be consciously aware. I am a white, middle class woman which influences how I view the world. My background in nutrition and my belief in the need to recognize larger contextual and structural issues in the experience of diabetes have focused my analysis. I have assumed that diabetes is a problematic process and that it is a significant experience in individuals' lives. I also believe that theory and practice should be interactive, and therefore I am trying to bridge my theoretical analysis with a practical application. I am trying to position my education based on a biomedical model and welcome alternate sociological ways of conceptualizing health and illness. These are only a few of my assumptions, and I am constantly trying to be

aware of my thought processes and where these are coming from.

There are many ethical issues involved in the research process. When we become characters in participants' stories, we change their stories. This requires a reflection about who we are as researchers in the stories of participants (Clandinin and Connelly, 1994). Furthermore, we must also recognize how the interpretation process portrays the respondents and how these results will affect the field of diabetes and in turn affect individuals who are living with diabetes.

These issues discussed merely skim the surface of the tremendous ethical and problematic issues inherent in the research process. It is impossible to resolve many of these issues but an open engagement with these issues and an incorporation of them into the research process provides the foundation for moral research.

7. REFERENCES

Allen, K.R., & Baber K.M. (1992). Ethical and epistemological tensions in applying a postmodern perspective to feminist research. Psychology of Women Quarterly 16, 1-15.

Benner, P. (1994). The tradition and skill of interpretive phenomenology in studying health, illness, and caring practices. In P. Benner (Ed.), Interpretive phenomenology, embodiment, caring, and ethics in health and illness (pp. 99-127). Thousand Oaks: Sage Publications.

Calhoun, C. (1995). The politics of identity and recognition. In C. Calhoun (Ed.), Critical social theory (pp. 193-230). Oxford, UK: Blackwell.

Callaghan, D., & Williams, A. (1994). Living with diabetes: issues for nursing practice. Journal of Advanced Nursing, 20, 132-139.

Canadian Diabetes Association. (1996). Your student with diabetes - a practical guide. (Brochure).

Cannon, L.W., Higginbotham, E., & Leung, M.L.A. (1988). Race and class bias in qualitative research on women. Gender and Society 2, 449-462.

Charmaz, K. (1987). Struggling for a self: identity levels of the chronically ill. Research in the Sociology of Health Care 6, 283-321.

Charmaz, K. (1991). Good days, bad days. New Brunswick, New Jersey: Rutgers University Press.

Charmaz, K. (1993, April). Studying lived experience through grounded theory realist and constructivist methods. Paper presented at Studying Human Lived Experience: Symbolic Interaction and Ethnographic Research, Waterloo, Ontario, Canada.

Charmaz, K. (1995). The body, identity, and self: adapting to impairment. The Sociological Quarterly 36, 657-680.

Clandinin, D.J., & Connelly, M.F. (1994). Personal experience methods. In N. Denzin and Y. Lincoln (Eds.), Handbook of Qualitative Research (pp. 413-427). Newbury Park, CA: Sage.

Clark, J. (1990). Health, Illness and medicine in Canada. Toronto: McLelland & Stewart.

Connelly M.F., & Clandinin D.J. (1990). Stories of experience and narrative inquiry. Educational Researcher 19, 2-14.

Conrad, P. (1987). The experience of illness: recent and new directions. Research in the Sociology of Health Care 6, 1-31.

Corbin, J., & Strauss, A.L. (1987). Accompaniments of chronic illness: changes in body, self, biography, and biographical time. Research in the Sociology of Health Care 6, 249-281.

Diabetes Control and Complications Trial Research Group. (1993). The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. The New England Journal of Medicine, vol.329, 977-986.

Diabetes Control and Complications Trial Research Group. (1995). Implementation of treatment and protocols in the Diabetes Control and Complications Trial. Diabetes Care, 18, 361-376.

Fife, B.L. (1994). The conceptualization of meaning in illness. Social Science and Medicine 38, 309-316.

Frank, A.W. (1991). For a sociology of the body: an analytical review. In M. Featherstone, M. Hepworth, & B.S. Turner (Eds.), The body social process and cultural theory (pp. 36-102). Thousand Oaks: Sage Publications.

Frank, A.W. (1995). The Wounded Storyteller. Chicago: The University of Chicago Press.

Geertz, C. (1983). Local Knowledge. New York: Basic Books Inc.

Goffman, E. (1963). Stigma: notes on the management of spoiled identity. Englewood Cliffs, NJ: Prentice Hall.

Goffman, E. (1973). Role distance. In A. Birenbaum & E. Sagarin (Eds.), People in places: the sociology of the familiar (pp. 121-137). New York: Praeger Publishers.

Gubrium, J.F., & Holstein, J.A. (1995). Individual agency, the ordinary, and postmodern life. The Sociological Quarterly, 36, 555-570.

Hernandez, C.A. (1991). The lived experience of Type I diabetes: implications for diabetes education. Unpublished doctoral dissertation, University of Toronto, Toronto, Ontario, Canada.

Hernandez, C.A. (1995). The experience of living with insulin-dependent diabetes: lessons for the diabetes educator. The Diabetes Educator, 21, 33-37.

Holstein, J.A., & Gubrium J.F. (1995). The active interview. Qualitative Research Methods volume 37. Thousand Oaks: Sage Publications.

Horney, S.J. (1986). The experience of diet in living with diabetes. Unpublished master's thesis, University of Toronto, Toronto, Ontario, Canada..

Hughes, E.C. (1945). Dilemmas and contradictions of status. American Journal of Sociology, 50, 353-359.

Kelleher, D. (1988). Coming to terms with diabetes: coping strategies and non-compliance. In R. Anderson & M. Bury (Eds.), Living with chronic illness: the experiences of patients and their families (pp. 137-155). London: Unwin Hyman.

Kelly, M.P., & Field, D. (1996). Medical sociology, chronic illness and the body. Sociology of Health and Illness 18, 241-257.

Kleinman, A. (1988). The illness narratives: Suffering, healing and the human condition. New York: Basic Books.

Kohler Riessman, C. (1993). Narrative Analysis. Newbury Park: Sage Publications.

Lang, G.C. (1989). "Making sense" about diabetes: Dakota narratives of illness. Medical Anthropology, 11, 305-327.

Lincoln Y.S., & Guba E.G. (1985). Naturalistic Inquiry. Beverly Hills: Sage Publications.

Maclean, H. (1991). Patterns of diet related self-care in diabetes. Social Science and Medicine, 32, 689-696.

Maclean, H., & Oram B. (1988). Living with Diabetes. Toronto: University of Toronto Press.

Maines, D.R. (1993). Narrative's moment and sociology's phenomena: toward a narrative sociology. The Sociological Quarterly, 34, 17-38.

- Mathieson, C.M., & Stam, H.J. (1995). Renegotiating identity: cancer narratives. Sociology of Health and Illness 17, 283-306.
- National Institutes of Health. National Institute of Diabetes and Digestive and Kidney Diseases. (1995). Diabetes in America (2nd edition). (NIH Publication No. 95-1468).
- Olesen, V., Schatzman, L., Droes, N., Hatton, D., & Chico, N. (1990). The mundane ailment and the physical self: analysis of the social psychology of health and illness. Social Science and Medicine 30, 449-455.
- Oram, B. (1992). The personal meaning of chronic illness within the context of everyday life: a case study of the experiences of people with insulin dependent diabetes mellitus. Unpublished doctoral dissertation, Ontario Institute of Education, Toronto, Ontario, Canada.
- Packard, N.J., Haberman, M.R., Fugate Woods, N., & Yates, B.C. (1991). Demands of illness among chronically ill women. Western Journal of Nursing Research 13, 434-457.
- Petrunik, M., & Shearing, C.D. (1988). The "I", the "Me," and the "It": moving beyond the Meadian conception of self. Canadian Journal of Sociology 13, 435-448.
- Peyrot, M., McMurry, J.F., & Hedges, R. (1987). Living with diabetes: the role of personal and professional knowledge in symptom and regimen management. Sociology of Health Care, 6, 107-146.
- Polkinghorne, D.E. (1988). Narrative knowing and the human sciences. Albany: State University of New York Press.
- Razack, S. (1993). Story-telling for social change. Gender and Education, 5, 55-70.
-

Robinson, I. (1990). Personal narratives, social careers and medical courses: analyzing life trajectories in autobiographies of people with multiple sclerosis. Social Science and Medicine, 30, 1173-1186.

Roth, J. (1963). Timetables. New York: The Bobbs-Merrill Company, Inc.

Saltonstall, R. (1993) Healthy bodies, social bodies: men's and women's concepts and practices of health in everyday life. Social Science and Medicine, 36, 7-14.

Somers, M.R. (1994). The narrative constitution of identity: a relational and network approach. Theory and Society, 23, 605-649.

Somers, M.R., & Gibson, G.D. (1994). Reclaiming the epistemological "other": Narrative and the social constitution of identity. In C. Calhoun (Ed.), Social theory and the politics of identity (pp. 37-99). Oxford, UK: Blackwell.

Turner, B. (1992). Regulating Bodies. London: Routledge.

West, P. (1990). The status and validity of accounts obtained at interview: a contrast between two studies of families with a disabled child. Social Science and Medicine, 30, 1229-1239.

Widdershoven, G.A.M. (1993). The story of life: Hermeneutic perspectives on the relationship between narrative and life history. In R. Josselson & A. Lieblich (Eds.), The narrative study of lives, volume 1 (pp. 1-20). Newbury Park: Sage Publications.

Williams, G.H., & Wood, P.H.N. (1988). Coming to terms with chronic illness: the negotiation of autonomy in rheumatoid arthritis. International Disability Studies, 10, 128-133.

Williams, G. (1984). The genesis of chronic illness: narrative re-construction. Sociology of Health and Illness, 6, 176-200.

Yoshida, K. (1993). Reshaping of self: a pendular reconstruction of self and identity among adults with traumatic spinal cord injury. Sociology of Health and Illness, 15, 217-245.

Appendix A: Overview of Insulin Dependent Diabetes Mellitus

Diabetes mellitus refers to a heterogeneous group of disorders characterized by high blood glucose levels. The four major types of diabetes mellitus that have been defined include insulin- dependent diabetes mellitus, non-insulin dependent diabetes mellitus, gestational diabetes mellitus and diabetes secondary to other conditions (National Institutes of Health (NIH), 1995).

Insulin-dependent diabetes mellitus (IDDM) is characterized by low to absent levels of plasma insulin, a hormone produced in the pancreas necessary for glucose metabolism. The incidence of IDDM in Canada is approximately 170 000 people, which is 0.5% of the population. Individuals with IDDM comprise 10% of the total population of individuals with diabetes (Canadian Diabetes Association, personal communication, January 10, 1997). IDDM usually occurs in individuals below the age of thirty, although it could occur at any age. IDDM management involves a balance of diet, insulin therapy, and exercise. The goal of treatment is to optimize glycemic control and to prevent acute metabolic complications and long-term complications (NIH, 1995).

There are various acute metabolic complications, but the most frequently discussed by the participants in the study are hypoglycemia and hyperglycemia. Hypoglycemia, insulin shock, and insulin reaction are different terms for the same phenomenon, a low blood sugar (Canadian Diabetes Association (CDA), 1996). Hypoglycemia ranges from a very mild lowering of blood glucose levels with minimal or no symptoms, to severe lowering of blood glucose levels and neurologic impairment. Hypoglycemia could result from various factors, including dosage of insulin, errors in dosage administered, timing of medications, delay in

meals, co-morbidity, intensity of glycemc control, and variability of insulin binding, degradation, and action (NIH, 1995). The symptoms can include cold, clammy or sweaty skin, pallor, lack of coordination, irritability, hostility, and poor behaviour, a staggering gait, fatigue, and eventual fainting and unconsciousness. Complains may include nervousness, excessive hunger, headache, blurred vision and dizziness, and abdominal pain or nausea (CDA, 1996). Milder cases of hypoglycemia can usually be treated with oral carbohydrates while more severe levels may require intravenous intervention (NIH, 1995).

Hyperglycemia, or high blood sugars, could result from too much food, less than the usual amount of activity, not enough insulin, or illness, and sometimes from no clear explanation. The earliest symptoms of high blood sugar are increased thirst and urination (CDA, 1996).

Long term complications of diabetes which have been observed are retinopathy, neuropathy, and kidney diseases. Increased incidences of heart disease, oral complications and possibly digestive diseases have also been observed in populations with diabetes compared to populations without diabetes (NIH, 1995).

The Diabetes Control and Complications Trial found that intensive therapy reduced the long-term complications of insulin-dependent diabetes. Intensive therapy involved multiple daily injections of insulin or continuous subcutaneous insulin infusion, flexible adjustment of insulin dose, frequent monitoring of glucose levels and diet, and behaviour change. Severe hypoglycemia occurred three times more often with intensive treatment (Diabetes Control and Complications Trial Research Group, 1995).

While optimal control is the biomedical goal in the management of diabetes, there are

many challenges to achieving this goal.

Appendix B: Interview Probe Questions

Things to Think About - First Interview

The group of us doing this study have wondered about some of these things. Do they remind you of anything in your life with diabetes?

Memories

Early stages of the disease

Changes in your life related to diabetes

Positives and negatives of life with diabetes

Diabetes and day-to-day life

Living a normal life with diabetes

Thoughts about your future and diabetes

First Interview - Sample Questions

The following questions may serve as ideas to help you probe particular areas the participant might choose to talk about.

Topics	Sample
1. To Begin	How long have you had diabetes? Why did you volunteer for this project? What is your experience of living with diabetes?
2. Early Stages	What do you remember most from the early stages? Do you remember the changes you had to make then? Can you describe a picture of yourself then?
3. Change	Has your experience of living with diabetes changed over time? What has changed? How have you made these changes? Do you feel it is a process of continual adaptation?
4. Memory	Are there parts of your experience of living with diabetes that stand out in your memory?
5. Crucial Things	What things do you see as crucial to living an optimal life with diabetes?
6. Positive, Negative	What are the most bothersome or difficult aspects of living with diabetes? Are there positive aspects?
7. Diabetes+Everyday Life	How does having to manage diabetes everyday affect other aspects of you life (i.e. your working behaviour; your relationship with others)? How do other aspects of your life affect managing diabetes?
8. The Future	What do you hope for in the future? Are there any things in your life with diabetes you would like to be different in two years time?

Things to Think About - Second Interview

The group of us doing this study have wondered about some of these things. Do they remind you of anything in your life with diabetes?

- Changes made in living with diabetes

- Who/What helps you live with diabetes

- Hindrances to living well with diabetes

- Stress and diabetes

- Work, Social life

- Family

- Sexuality

Things to Think About - Second Interview

The following questions may help you to think more about some of your own experiences:

Think about what life would be like to not have diabetes. How would your day-to-day life be different? What other things would be different?

What are the differences between the way you live your life and the way you see other people who do not have diabetes living their lives (or the way your life was before you had diabetes)? How do you feel about these differences?

Is what you are experiencing now different from what you experienced in the past? How is it different? Maybe it would help if you thought about what your life was like a number of years ago (2,5,10 years ago). What you were doing? Where were you living?

Can you identify any major life changes that you have faced (i.e. changing jobs, getting married, having a family, etc.)? Have these changes had an impact on your management of diabetes?

What/who has helped you learn to live with diabetes? What/who has not been helpful in learning to live with diabetes?

Are you aware of stress in your life? Does it affect your ability to manage diabetes? What are the sources of stress?

Think about your surroundings - where you work, where you live, and who you socialize with. Is your experience affected by your surroundings. If so, how?

How has your family responded to your developing diabetes? What is their role in providing help for you? Do other members of your family have diabetes? How has this influenced your experience, if at all.

The group of us doing this study have wondered about some of these things. Do they remind you of anything in your life with diabetes?

- Diabetes Management : Diet, Medication, Exercise

- Diabetes Control

- Complications associated with diabetes

- Reactions to health professionals (e.g., doctors, nurses,
dietitians)

- Teaching/Advice

Things to Think About - Third Interview

The following questions may help you to think more about some of your own experiences:

What are the things that you do everyday to manage diabetes?

What are your reactions to each of these tasks?

How do you manage your food intake? What is this like to do?

What helps you? What hinders?

What does "control" mean to you, if anything?

What role does each of the following play in controlling diabetes: diet, insulin/pills, exercise, monitoring blood sugar levels.

If control is important to you, do you lose out on other parts of your life (social, financial, physical, emotional)? What are the advantages of maintaining good control?

Does balance as an idea mean anything to you? What does it mean?

What do you think about when you see the words "complications of diabetes"?

What is it like to live with the unpredictability of potential future complications?

What is your reaction to the health professionals who have been involved in helping you manage diabetes? How have you reacted to them? Could they have been more helpful? If so, how?

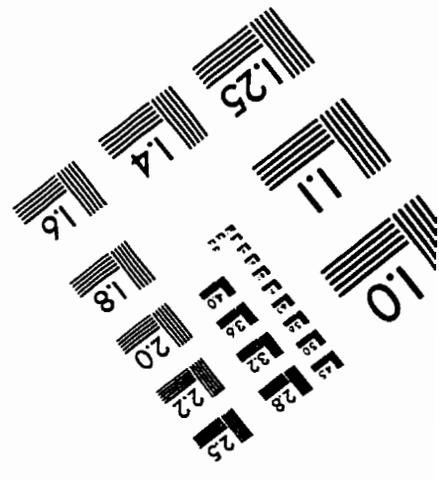
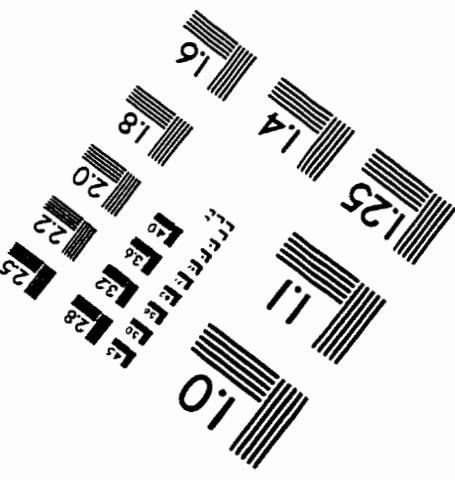
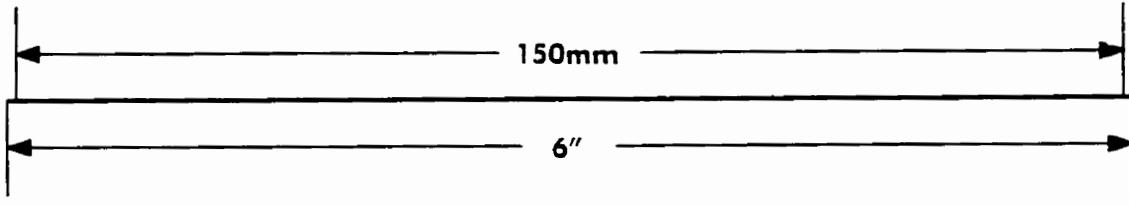
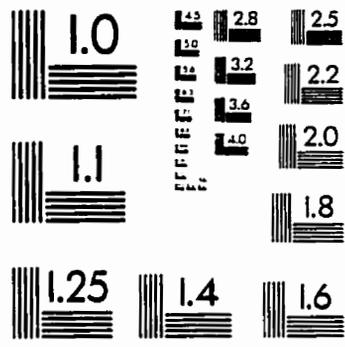
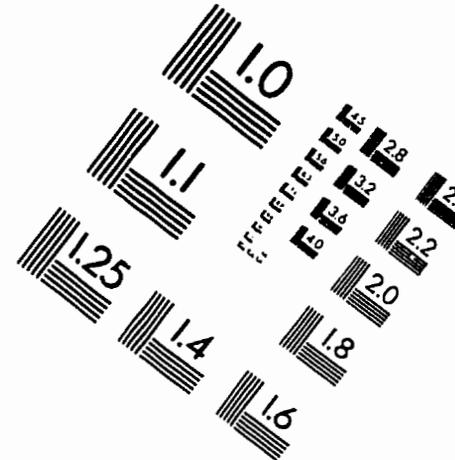
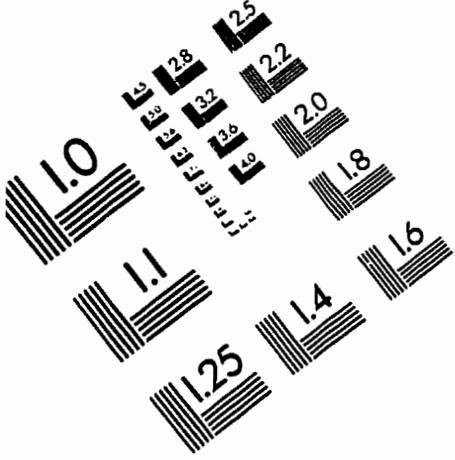
How have you learned to live with diabetes? How have you found out useful information?

Who has been involved in teaching you about managing diabetes?

What is your reaction to the teaching and advice you have received?

If you were asked to give advice to another person with diabetes, what would you say to them?

TEST TARGET (QA-3)



APPLIED IMAGE, Inc
1653 East Main Street
Rochester, NY 14609 USA
Phone: 716/482-0300
Fax: 716/288-5989

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