INTEGRATING DIABETES INTO EVERYDAY LIFE:

THE EXPERIENCES OF FATHERS

by

Kathryn Thomson

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ABSTRACT

The experiences of fathers of children with diabetes is a little understood, and rarely addressed, area. The purpose of this study was to explore and describe the processes through which the father assimilates his child's diabetes into his life. A qualitative, modified grounded theory research approach was used to identify the father's experiences with childhood diabetes. Data were obtained through in-depth audiotaped interviews with ten fathers of pre-adolescent children who had insulin-dependent diabetes mellitus for three to nine years.

Qualitative data analysis led to the development of a beginning substantive theory titled: Integrating diabetes into everyday life: The experiences of fathers. This process was conceptualized in three phases: discovering the meaning of diabetes, reordering patterns of daily living, and internalizing change. Movement through these phases was achieved through the father's emotional work, role work, and cognitive work. These concepts and processes are articulated in the theory of integrating diabetes. This theory provides a beginning framework for the description of the experiences of fathers of children with diabetes.

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CHAPTER ONE

STATEMENT OF THE PROBLEM

Introduction

One in six hundred children and adolescents in Canada will develop insulin-dependent diabetes mellitus (IDDM), the most common and complex childhood metabolic disorder (Daneman, 1985). IDDM is characterized by little or no endogenous insulin secretion which creates a lethal disturbance in carbohydrate, protein, and fat metabolism. Without daily injections of exogenous insulin, the child with IDDM would experience hyperglycaemia and ultimately succumb to ketoacidosis (Knowler, Everhart & Bennett, 1985).

Treatment of IDDM with exogenous insulin began 70 years ago following the discovery of insulin. Since that time, there has been a proliferation of knowledge and technology related to the care and management of IDDM. However, insulin administration alone does not ensure health. Insulin must be delicately balanced with the child's energy requirements, diet, and activity level. This balance is achieved by numerous and complex care-taking tasks. These tasks require

deliberate thought and action for normally spontaneous activities such as eating, drinking, sleeping, and recreation. The goal of care is to achieve near-normal blood sugars through adherence to a daily schedule that includes six meals, two to four insulin injections, four to six blood tests, urine testing, and regular pre-planned exercise. On a minute-to-minute basis the child and parent must attend to all bodily cues and be prepared to act in the event of an abnormal blood sugar.

The rewards of these intensive diabetes care-taking tasks are nebulous. Continuous care and monitoring of the child with diabetes minimizes, but does not prevent, acute hypoglycaemia, hyperglycaemia, and ketoacidosis. Long term complications can also occur; microvascular and macrovascular complications of diabetes lead to major disability and mortality in individuals who would be otherwise healthy (Health and Welfare Canada, 1985).

Care of the child with diabetes occurs in the home. The role of the father in child care has expanded during the past two decades; it is assumed that men are psychologically able to participate in a

full range of parenting behaviours which will be positive for both the father and the child (Fein, 1978; Pleck, 1979; Rotundo, 1985). The health care system supports the expanded role of the father and has adopted a philosophy of family-centered care. It is expected that both parents will accept responsibility for the care, management, and support of their child with diabetes (Belmonte, 1985; Benoleil, 1975; Daneman, 1985). This philosophy of care is perpetuated in spite of a limited understanding of how these expectations, and the child's diabetes, impact upon the father.

Fathering

Until the 1970s, the father's role was primarily the provider or breadwinner; involvement with caretaking was viewed as less than masculine (Boyd, 1985; Gardner, 1943). However, in recent years, economic and societal changes have caused shifts in the roles and responsibilities of the father. The father is now viewed as an important participant in child-rearing (Hanson & Bozett, 1986; Lamb, 1986; Lewis & Sussman, 1985; Rotundo, 1985).

Generally, fathering research has been conducted

in the field of sociology and family studies. Three predominant areas of study are addressed in this research: 1) the father's actual participation in child care (Baruch & Barnett, 1981, 1986; Lamb, 1986; Redina & Dickerscheid, 1976; Russell, 1978, 1982; **Sawin & Parke, 1979**); 2) the factors that influence the father in his parenting role (Cowan & Cowan, 1987; Feldman, Nash, & Aschenbrenner, 1983; Radin, 1982; Russell, 1986); and 3) the impact of the father's involvement on the child (Clarke-Stewart, 1978; Earls, 1976; McBride, 1989; Radin, 1982). Few studies have addressed the effects of actual, or expected, paternal involvement in child-care. Russell's (1986) review of research involving fathers' who were full time, or fifty percent care-givers, found that fathers' experienced positive effects including a sense of closeness and sensitivity to their children, and increased self-esteem and satisfaction. Negative effects included difficulty adjusting, and frustration, tension, and conflict related to the demands associated with a child-care role (Russell, 1986). Other researchers have also suggested negative effects for the father involved in child care. Fathers who

participated in child care reported dissatisfaction with their wives, role strain related to their careers, and stress due to inconsistent expectations of the family and society (Baruch & Barnett, 1986: Lein, 1979).

Health Care Approaches to Fathering

Health care literature examining the experiences of fathers adopting a child-care role, has been addressed in the area of maternal-child health. This literature primarily addresses the experiences of expectant, and new, fathers and indicates that taking on new fathering roles may be problematic for men (Feldman, 1987; Hawkins & Belesky, 1989; Humenick & Burgen, 1987; Shapiro, 1987). For example, Jordan (1990) found that men entering fatherhood were frustrated by a lack of support from their mates, health care providers, and society. This same lack of support of men in their fathering role has also been experienced by men who are taking on roles that are considered "non-traditional" (Russell, 1982).

Health care literature related to childhood

illness, including diabetes, has largely neglected the experiences of fathers. There is little known about the father's response to his child's diabetes and the resultant care-taking tasks. Studies involving fathers are complicated by several methodological problems. Typically, fathers have only minimal involvement in research studies; researchers' attempts to understand the father's response have been thwarted by limitations such as small, homogeneous, self-selected samples (Allen, Tennen, McGrade, Affleck, & Ratzan, 1983; Fallstrom, 1974; Koski, 1969; Kovacs, Finkelstein, Feinberg, Crouse-Novak, Paulauskas, & Pollock, 1985). Articulation of the father's response has been further complicated by a continued reliance on maternal reports in spite of validity concerns (Anderson & Aushander, 1980; Boyd, 1985; Cronenwett, 1982; Fisher, Delamater, Bertelson, & Kirkley, 1982; Hauser & Pollets, 1979; Masters, Curreto, & Mendlowitz, 1983). The limited research that has examined both parents' experiences reveals incongruence in maternal and paternal experiences. It has been suggested that this incongruence may be due to sex differences in: emotional responses (Fallstrom, 1974; Kovacs et al.,

1985; McCubbin, McCubbin, Patterson, Cauble, Wilson, & Warwick, 1983; Tavormina, Boll, Dunn, Luscombe, & Taylor, 1981); coping behaviours (Powers, Gaudet, & Powers, 1986); parenting, emotional expressiveness, disclosure (Cook, 1988); and parental care-taking responsibilities (Cummings, 1976; Etzwiler & Sines, 1962).

The limited research that has examined the father's experience with his child's illness suggests that the father's response to the illness may have significant ramifications for the father himself, the child, and the other family members. The demands of diabetes may cause emotional stress (Fallstrom, 1974; Koski, 1969; Kovacs et al., 1985) and interfere with the father's enactment of other roles (McKeever, 1981). Sullivan's (1979) study revealed that the father's relationship with his child was positively related to the self-esteem and over-all adjustment in adolescent females with diabetes ($p=.001$); her study demonstrated that there are more significant positive correlations between self-esteem and adjustment in terms of the relationship with the father than with the mother. Although these findings support the importance of the

father, they have not been replicated with groups other than adolescent females.

Researchers have reported the influence that both the father's and the mother's response to the diabetes has on the total family. Parental responses to the diabetes and the care-taking tasks have been shown to effect the control of the child's diabetes. Any omission of a care-taking task can threaten the child's health and ultimately his/her life (Johnson & Rosenbloom, 1982). The emotional tone of the home and the ability of the parents to cope with the diabetes, work through conflicts, and support each other, may influence the control of the child's blood sugar (Fallstrom, 1974; McKelvey, Waller, Stewart, Kennard, North, & Chipman, 1989; Minuchin, Rosman, & Baker, 1978; Newbrough, Simpkins, & Maurer, 1985; Orr, Golden, Myers, & Murrero, 1983; Swift, Seidman, & Stein, 1967; Tarnow & Tomlinson, 1978).

The literature also suggests that the parents' response to a chronic illness has significant ramifications for individual family members. The strain that the parents' experience may ultimately influence the marital relationship (Futcher, 1988;

Kupst & Schulman, 1988; Sargent, 1983), and the response of the well siblings (Brett, 1988; Feeman & Hagen, 1990; Krulik, Holaday, & Martinson, 1987).

In summary, although the significance of the father with respect to his child's diabetes is acknowledged, there is little actually known about his responses to, and experiences with, his child's diabetes. A limited amount of literature related to fathering suggests that expecting a father to adopt an active role in child care may be problematic. Health care literature also reveals that the father's response to his child's illness exerts an influence on himself and all members of the family. However, there is little known about the father's actual response to the diabetes and his experiences in adopting a care-taking role. The research suggests that the father's experience is qualitatively different from the mothers', therefore, extrapolation from studies of the maternal response does little to illuminate the paternal experience.

Purpose of the Study

The purpose of this research was to explore and describe the father's responses to, and experiences with childhood diabetes using a grounded theory approach. The study addressed the actual lived experiences of fathers who have a child with IDDM.

The central question of this study was: what is the process through which fathers' assimilate their child's diabetes into their lives. This question was general in nature in order to promote a comprehensive qualitative data base that would reflect experiences that were significant to the fathers themselves.

The research was guided by the following questions:

1. How does the father describe the experience of being a parent of a child with diabetes?
2. What are the father's emotional responses to his child's diabetes and diabetes care?
3. How do the father's responses to the diabetes influence his interactions inside and outside the family?

4. How do the father's responses to his child's diabetes change over time?

5. How do the responses of others influence the father?

Conceptual Framework

Consistent with a grounded theory approach, the theoretical basis for this study was symbolic interactionism. Symbolic interaction (SI) theory is an approach to the study of human behaviour that emphasizes human interactions and the way that these interactions shape both the individual and the society. Interactions influence the individual's construction of the meanings and perceptions that arise out of social activity; these individual constructions will ultimately influence behaviour and the individual's perceptions of that behaviour.

Symbolic interaction theory is based on three premises (Blumer, 1969). The first premise is that human beings act toward things on the basis of the meanings that the things have for them. "Things" may include physical objects, other human beings,

categories of human beings, institutions, guiding ideals, activities of others, or any situation that the individual may encounter (Blumer, 1969, p. 2). The second premise is that the meaning of these things arises out of interactions between people. Blumer (1969) views meanings as social products that are formed in, and through, the defining activities of people as they interact (p. 5). Finally, the third premise is that these meanings are developed and modified by a process of interpretation. Handling and modifying meaning occurs through interactions that individuals have with themselves as they select, check, suspend, regroup, and transform the meanings of a specific situation (Blumer, 1969, p. 5).

Blumer (1969) incorporates these three premises into six "root images" or the basic theoretical perspective of SI theory. Each of the six root images will be discussed briefly.

1. The nature of human society or group life: According to SI theory, individuals, groups, and society exist in an ongoing process of action. People, individually or collectively, constantly engage in activities as they encounter one another and the

various situations of their lives (Blumer, 1969, p. 7).

2. The nature of social interaction: SI theory views social interaction as the process that directs human conduct. Humans guide their behaviour by taking account of what others are doing, are about to do, or expected to do. Based on these interpretations individuals may fit their actions into the actions of others (Blumer, 1969, p. 8).

3. The nature of objects: "Objects" include: physical objects such as a tree; social objects, such as a friend; and abstract objects, such as ideals. The nature of an object arises out of the meaning that it has for an individual; this meaning is derived from the way that the object is defined by the individual or others with whom the individual interacts (Blumer, 1969). Therefore, as a result of interactions, individuals name, define, classify, and revise their meaning of objects as they interact.

4. Human beings as acting organisms: The concept of "self", is central in this root image. One's self is the way that an individual describes to himself/ herself, his/her relationships to others in a social process (Stryker, 1972). This definition of self

develops through self reflection and social interactions. Because of the self, human beings are both active and reactive during the process of social interaction. Individuals are reactive in that they respond to others during social interaction. However, individuals are also active in their indications that they make to others and their interpretations of social interactions.

5. The nature of human action: SI theory views human behaviour as self-directed and based on personal interpretations, meanings, responses, and action decisions. The actions of individuals, or groups, arise from the defining processes that are used in the specific situation.

6. The interlinkage of human group actions: Individuals in a society share many meanings regarding rules, norms, and values; these shared meanings account for recurrent and stable patterns of human behaviour. Changes in social processes may allow for the redefining of theses shared meanings; in this case, change in behaviour can occur.

To summarize, Blumer's (1969) clarification of the premises of SI theory, and his elaboration of the root images, outlines a theoretical framework for the study of human behaviour. SI theory proposes that human behaviour is the result of individuals' interpretative and defining activities that occur as they actively interact with themselves and others. The outcome of these interactions is the development of individual meanings and perceptions of objects, including oneself; these meanings will influence human behaviour. In essence, human behaviour originates from personal meanings and perceptions which are derived from internal and external interactions.

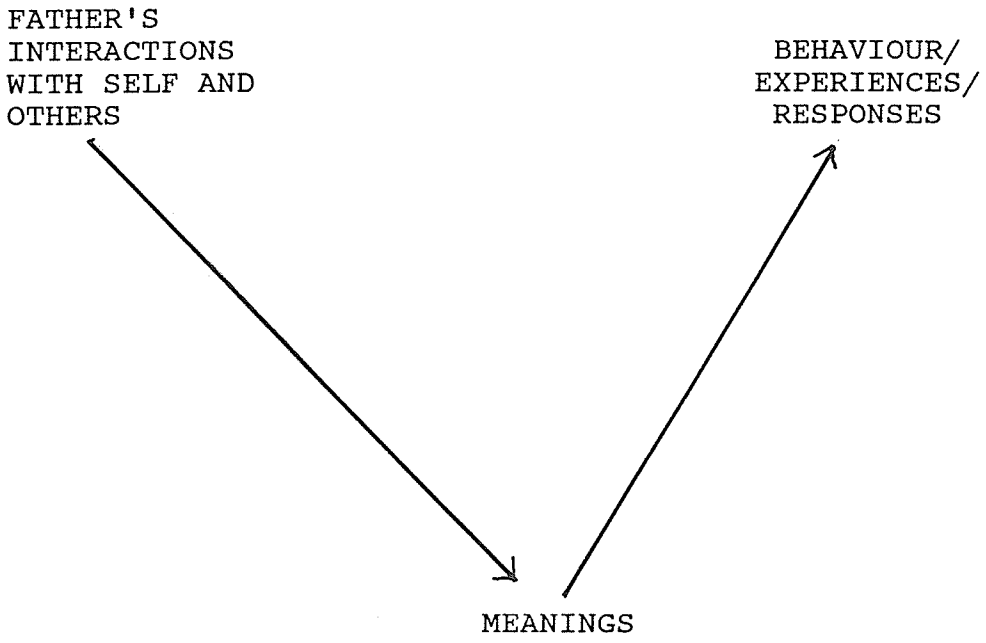
This research is sensitized by two key concepts arising out of above discussion of the interactionist approach to human behaviour: 1) definition of the situation, and 2) self. Waller (1970) describes definition of the situation as a subjective process that involves an exploration of: possible behaviours, the limitations which the situation imposes upon behaviours, the attitudes of others, the situational contexts, and preexisting norms (p. 162). Through this

process of "defining", the individual develops an attitude toward the situations of his/her own life.

The concept of "self" is described as a dynamic process of being aware of, and defining, oneself in a particular way; "self" will affect both the interpretation of interactions and actions (Burr, Leigh, Day, & Constantine, 1979). Included in the individual's definition of self, is the definition of roles and how they will be enacted in given situations. These roles are created through family interactions and societal expectations (Schvaneveldt, 1966).

Based on the premises and assumptions of S.I. theory, the father of a child with diabetes will ascribe meanings to the diabetes and its care-taking tasks based upon internal and external interactions and his interpretation of those interactions. From a symbolic interactionist's perspective, it is these meanings that will direct the process of the father's assimilation of his child's diabetes into his life. This symbolic interactionist approach to the study of the father's experiences is conceptualized in Figure 1.

FIGURE 1: A SYMBOLIC INTERACTIONIST APPROACH TO THE STUDY OF THE FATHER OF A CHILD WITH IDDM



Definition of Situation

- possible behaviour
- limitations imposed by situation
- attitudes of others (family, friends, health care system)
- situational contexts
- pre-existing norms (societal, family of origin, own family)

Self

- view of own roles and how they will be enacted (self as husband, father, care-giver, etc.)
- view own capabilities

Conclusion

Childhood diabetes is a chronic, complex condition requiring unrelenting attention to numerous care-taking tasks. The majority of this care occurs in the home as the parents are expected to assume responsibility for the on-going management of their child's illness. This expectation exists in spite of a limited knowledge base regarding the father's response to his child's diabetes and its care-demands. This study attempted to explore and describe the processes through which fathers assimilate their child's diabetes into their lives.

Symbolic interaction theory provided a conceptual framework for the study of the father's response to his child's diabetes. Within this framework, evolution of the father's responses to his child's diabetes that occurred as a result of his interactions with himself and others were studied. These interactions were explored to help understand the meaning that the father ascribed to the diabetes and its care-taking tasks.

CHAPTER TWO

REVIEW OF THE LITERATURE

Introduction

The purposes of an initial review of the literature in a grounded theory approach are to: sensitize the researcher to the present state of knowledge; stimulate questions; determine the scope, range and complexity of a phenomenon; and assist with theoretical sampling (Chenitz, 1986; Sandelowski, Davis, & Harris, 1989; Stern, 1980; Strauss & Corbin, 1990). In keeping with these aims, fathering literature was broadly reviewed prior to initiating the study.

A review of literature (1965 -1990) related to fathering and well child care, ill child care, and diabetes care revealed comparatively little research that could be used to build a comprehensive knowledge base regarding the father's response to the care of his child with diabetes. Generally, the literature related to the topic of fathers has addressed emotional responses and roles inside and outside of the family.

In keeping with these themes, the review of the literature has been organized under three main areas: 1) the father's emotional response to the demands of diabetes, 2) the father's response to diabetes: influences on interactions outside the family, and 3) the father's response to diabetes: influences on interactions inside the family. In each topic area, fathering a well child, an ill child, and a diabetic child was reviewed.

Much of the research addressed in this review is presented conditionally. Many of the studies are limited by an underlying assumption that chronic illness results in maladaptation; much of the research has also been based on white middle class samples, used unsystematic sampling approaches, and relied on psychometric instruments that may not be valid for male respondents.

The Father's Emotional Responses to the Diabetes

When a child has diabetes, the father, like the mother, is expected to adapt to the diabetes and incorporate the diabetes care tasks into normal parenting behaviours. Diabetes care becomes synonymous with child care. Three general areas of literature were reviewed in order to assess the father's responses to the diabetes and the resultant care: 1) the father's response to well child care; 2) the father's response to diabetes and chronic illness; and 3) the father's perception of self as a care-giver.

The Father's Response to Well Child Care

Although there is much literature examining the father's involvement in family work and the outcomes of that work vis-a-vis the spousal relationship and the children, there is only a limited amount of research exploring the paternal response to well child care. Three studies that have specifically addressed the emotional impact of child care on the father will be reviewed. Baruch and Barnett (1986) conducted a cross-sectional quantitative study examining the relationship

between parental participation in family work (parent-child interaction, child care, home chores) and self-esteem, life satisfaction, and satisfaction with the marital role. These authors found that parental participation was experienced as a different phenomenon by fathers and mothers; fathers were experiencing increasing involvement in "non-traditional" family work while mothers were relinquishing components of their traditional role. These changes in parental participation affected each of the parents as individuals and their satisfaction with marital roles. Findings specific to the father's response included: participation in child care resulted in a personal sense of involvement and competence; and child care involvement led to role strain.

These findings are supported in another quantitative study conducted by Russell (1982) who examined the impact of shared care-giving on Australian fathers. The fathers in this study assumed fifty percent or more responsibility for the children. Similar to the study by Baruch and Barnett (1986), Russell found differences in the maternal and paternal responses. Mothers were affected by the loss of

contact with children, negative sanctions of family members, positive sanctions of peers, and improved personal well-being derived from employment. The responses of fathers in a child-care role included: stress related to the demands of the role; negative reactions from others; and marked positive changes in their relationship with their children.

A third study conducted by Lein (1979) offered a similar perspective regarding the father's responses to participation in family work. This author used extensive interviews with 25 men to explore men's response to the pressures that are placed on them to increase their involvement in housework and child care. Lein found that fathers were reluctant to give up their primary breadwinner role. Fathers also reported stress surrounding inconsistent societal and family expectations related to the male role in family work.

The results of these studies are limited by the fact that representative samples were not used. However, these findings suggest that fathers may have both positive and negative responses to involvement in well child care.

The Father's Response to Diabetes and Chronic Illness

There is little research examining the father's perceptions and emotional responses to diabetes and its care demands. Fallstrom (1974) and Kovacs et al. (1985) each conducted studies that examined the mother's and the father's responses to their child's diabetes and care demands. These authors' found that mothers often reported difficulties coping with the burdens of daily care. When compared to a limited sample of fathers, mothers reported more anxiety, depression, and distress. Both studies also revealed that fathers experienced emotional upheavals but this effect was less than that experienced by mothers.

Only two empirical studies have specifically examined the paternal response to chronic illness. Cummings' (1976) conducted a descriptive, quantitative study that examined the "psychological life" of the fathers of handicapped children. His sample consisted of 240 fathers of children who were mentally retarded, diabetic, neurotic, or healthy. These fathers completed four self-administered, paper and pencil tests designed to assess personality variables (mood, self-esteem, interpersonal satisfactions with family and others,

child rearing attitudes). Reliability and validity estimates were not provided. The sample of fathers of ill children experienced significant negative effects such as depression, a sense of incompetence, and dissatisfaction with relationships.

A second qualitative study (McKeever, 1981), described the experience of fathering a chronically ill child. McKeever interviewed ten fathers of children with hemophelia, thalassemia major, asthma, and renal disease who were seen in a home care department of a large hospital. Paternal grief, increased psychosomatic complaints, and a sense of uncertainty were reported by the fathers in this study.

Although the studies conducted by Cummings (1976) and McKeever (1981) suggest a negative emotional impact, the findings must be interpreted with caution. McKeever's sample did not include fathers of diabetic children or any other chronic illness that requires similar daily care-taking demands. Lack of information regarding the validity and reliability of measures used in Cummings' study clouds interpretation of his findings.

Other authors who have conducted research exploring the responses of parents to their diabetic or chronically ill child have reported incidental findings regarding the father's response. Fathers have been described as "emotionally divorced" from child care (Tavormina et al., 1981), as domineering and neglectful (Swift et al., 1967), and as uninvolved and selective in their involvement with their ill child (Etzwiler & Sines, 1962). In each of these studies, the findings cannot be generalized due to sample size limitations.

The Father's Perception of Self as a Care-giver

The father's response to the diabetes care-taking demands may also influence his self-image. A relationship between the father's sense of self-competence and participation in care-taking behaviours with well children has been proposed in the literature. Fathers who feel inexperienced and incompetent in child care tend to find child care problematic and withdraw from it; this withdrawal, in turn, contributes to a further sense of incompetency (Baruch & Barnett, 1986; Entwisle & Doering, 1988; Hawkins & Belsky, 1989; McHale & Huston, 1984; Partridge, 1988).

Cummings (1976) found a similar trend in fathers of handicapped children. This author speculated that a father's limited participation in the care-taking of the mentally retarded child is associated with a sense of incompetency which may, in turn, further contribute to limited participation.

In summary, the literature suggests that the father may be influenced by his child's diabetes. Studies addressing paternal responses to well child-care have found that fathers' experience both positive and negative outcomes, while literature exploring paternal responses to ill child care have found mainly negative responses. A secondary finding of studies examining fathers of well children, suggests that paternal responses are qualitatively different from maternal responses. This finding was significant to the study of the father of a diabetic child; maternal reports and psychometric instruments developed for studies of mothers' responses may not be valid for fathers.

The Father's Response to Diabetes: Influences on Interactions Outside the Family

The literature related to well child care and ill child care does not specifically address the relationship between paternal responses and interactions outside of the family. In order to explore this area, two bodies of research were reviewed: paternal interactions outside of the home in families with well children; and paternal interactions outside of the home in families with ill children.

Interactions Outside the Family (Well Children)

Research examining fathers of well children has revealed that fathers' major roles remain outside of the home; fathers have minimal interaction and responsibility with their children (Baruch & Barnett, 1981; Clarke-Stewart, 1978; Cowan & Cowan, 1987; Entwisle & Doering, 1988; Ninio & Rinott, 1988; Radin, 1982; Redina & Dickerscheid, 1976).

There has been no research that specifically addresses the relationship between paternal responses to child care and interactions outside of the family. However, several studies have reported findings

suggesting that interactions outside of the family may be influenced when the father is involved in care-taking. Research has shown that fathers involved in family work are confronted with unclear expectations, and limited community, social, and family support which results in role strain and conflicts, emotional stress, and feelings of inequity (Baruch & Barnett, 1986; Lein, 1979; Lewis & Sussman, 1985; McBride 1989; Radin, 1982; Russell, 1982). These studies have suggested that fathers who do participate in parenting experience "role strain" and stress as they attempt to fulfil their paternal role.

Interactions Outside the Family (Ill Child)

Research that addresses how the father's response to illness impacts on his roles outside the family has not been identified. However, incidental findings related to the impact of an illness on the father's career and his activities outside of the home have been reported.

McKeever (1981) reported that all fathers in her sample felt that their career mobility had been negatively affected by their child's chronic illness.

However, cystic fibrosis (CF) researchers have reported less significant career impacts. Phillips, Bohannon, Gayton, and Friedman (1985) interviewed 29 fathers of children with CF and found that only 21 percent reported that their career potential was adversely affected by their child's illness. Meyerowitz and Kaplan (1964) found 33 percent of fathers in their sample reported that their child's illness had negatively influenced their career. Interpretation of these studies is limited by methodological problems. McKeever, and Phillips et al., used small non-representative samples. Meyerowitz and Kaplan's findings may be irrelevant due to the changes that have occurred in family occupational roles since they conducted their study.

Researchers have reported findings that suggest that childhood chronic illness may influence fathers' social interactions outside of the family. Fathers of children who are mentally retarded have reported dissatisfaction in their relationships with neighbours, decreased social activities, and limited involvement in community life (Cummings, 1976; Price-Bonham & Addison, 1978). Fathers of chronically ill children reported

reduced social and leisure activities (McKeever, 1981).

Studies exploring the impact of cystic fibrosis (C.F.) on the father's relationships outside of the home have yielded contradictory results. Turk (1964), reported that parents of a child with C.F. experienced social deprivation and disruption in interpersonal relationships. Conversely, Phillips et al. (1985) found that 65 percent of families of a child with C.F. reported no change in their social life. These contradictory findings may be due to differences in how these variables were measured and the contextual social factors relevant to the times that these studies were conducted.

In summary, there is limited research examining the relationship between the father's response to diabetes and his interactions outside of the family. Related research suggests that changes in relationships outside of the family may occur; however, these findings are inconsistent and inconclusive. Studies conducted prior to the last decade may be irrelevant. The father's interactions outside of the family may be socially determined and change in response to changing social norms and patterns.

The Father's Response to Diabetes: Influences on Interactions Inside the Family

The father's response to his child's diabetes and the care demands may influence his participation in child-care, and his interactions with his well children and his partner. Each of these areas will be examined.

Interactions Inside Family: Child Care

Research has demonstrated that fathers have had little involvement in well child care (Baruch & Barnett, 1986; LaRossa, 1988; Ninio & Rinott, 1988; Russell, 1982) in spite of their apparent capability (Jones, 1985; McHale & Huston, 1984; Sawin & Parke, 1979). Researchers and authors have shown that capability does not predict the father's involvement in child care activities; child care appears to be reflected in the father's perceptions of himself, interactions within the family, and the broader society (Baruch & Barnett, 1981; Cowan & Cowan, 1987; Feldman et al., 1983; Lewis & Sussman, 1985; Reiber, 1976; Russell, 1982).

Research exploring the father's response to well child care and interactions in the family was comprehensively addressed by Cowan and Cowan (1987). These authors conducted a longitudinal study exploring men's involvement in parenthood; many of their findings revealed the importance of interactions in the family. A convenience sample of 62 couples was obtained from a specific geographical area. Each parent completed paper and pencil instruments and participated in a interview during their first pregnancy, at six months post-partum, and at 18 months post-partum. Three findings that are relevant to the father's response to child care and interactions in the family were: 1) fathers did become involved in child care at some level; however, that involvement was dependent on factors related to their satisfaction with themselves and their marriage prior to the birth of the baby; 2) father's who were satisfied with their role, reported greater satisfaction with their marital relationship, higher self-esteem, held more child-centered parenting attitudes, and had greater involvement in child-rearing; and 3) barriers to child care roles included a lack of role models, limited support from the family of

origin, a low self-esteem or sense of incompetence, and maternal responses that were critical of the father.

Cowan and Cowan's (1987) findings suggest that interactions within the family influence the father's response to child care. It is not clear if the father's responses, in turn, influence family interactions. Extrapolation of these findings to fathers of children with diabetes may not be appropriate due to the small, non-representative sample of fathers of well children.

The father's response to child care during illness has not been explored extensively. Fathers are involved with problem solving (Singer & Farkas, 1989), with home care (McKeever, 1981) and with hospital care (Knafl & Dixon, 1984); however, detailed descriptions of the father's involvement and his response to that involvement are not discussed in these studies.

Research has not been undertaken to explore extensively paternal participation in diabetes care-taking; only two studies have addressed this issue (Etzwiler & Sines, 1962; Wagner, 1987). In a study 29

years ago, Etzwiler and Sines (1962) administered paper and pencil questionnaires to 53 fathers and 62 mothers of children attending a diabetic camp in order to study diabetes management practices. These fathers were only minimally involved in care due to a lack of knowledge, a lack of opportunity, and a personal choice. These findings may not be applicable because only 53 percent (n=28) of the total sample of fathers completed the all of the questionnaires. Also, the nature of father participation may have changed during the past three decades due to expansion in diabetes education programs and social changes in fathering roles.

More recently, paternal involvement in diabetes care was described by Wagner (1987) who explored the role of the father in relation to his child's adjustment to IDDM. Forced-response questionnaires were administered to a self-selected, homogenous sample of 40 men. Two major areas were assessed: parent involvement in child care; and parent involvement in diabetes care. Wagner (1987) found that fathers had limited involvement in the practical issues of diabetes care; however, they were involved in many activities that were unrelated to practical care. Although these

findings are limited by a non-representative sample and unreported reliability and validity estimates for the questionnaires, the results suggest that exploration of the father's involvement may need to move beyond simple practical child-care tasks. Father involvement may occur, but the nature and the family interactions associated with the fathers involvement have not been articulated.

Interactions Inside Family: Individual Members

There is also only limited research exploring the father's response to the demands of the diabetes and his interactions with family members. A small amount of research related to well child care has demonstrated that interactions between the father and mother can influence the father's response to the responsibility of child care. Several studies examining interactions in families with well children have found that maternal support of the father was positively related to the ease and degree of paternal involvement (Cowan & Cowan, 1987; Palkovitz, 1984; Reiber, 1976). However, this relationship has not been explored in families with ill children.

Research examining marital relationships in families with well children also suggests that increasing paternal involvement in child care may contribute to marital dissatisfaction. Baruch and Barnett (1986) found that fathers who were involved in child care were more dissatisfied with their wife's role than those fathers who were less involved. Russell (1982) reported similar marital tensions in families where the father was involved in child care at least fifty percent of the time. This author reported that these couples experienced a marked increase in marital stress during the time that father involvement increased. However, this stress was usually resolved within several months.

Research examining the marital relationship in families of a child with diabetes has been inconclusive. Crain, Sussman, & Weil (1966) found that parents of children with diabetes experience low levels of marital integration. Their sample of couples revealed marked tension and conflict in family roles. However, difficulties in the marital roles have not been found in all research. Kovacs et al. (1985) conducted a longitudinal study of families of children

with diabetes and found that one year following the diagnosis, there were no changes in marital harmony. These contradictory findings may be due to a 19 year time span between the two studies or the use of different measures to determine marital impacts.

There is a similar lack of research on the father's response to the diabetes and his role with his well children. Again, the father's interactions with well children have not been explored. However, related studies have revealed that the father perceives altered interactions with well children. Cummings (1976) reported that fathers of handicapped children had low levels of satisfaction with their father role as it related to their other children. McKeever (1981) also found that fathers reported concern about their ability to parent their well children.

In summary, the father's response to his child's illness and interactions within the family has not been comprehensively addressed. Research addressing both well and ill child care suggests that the father has only a minimal role in child care and that the father's role in ill child care may be difficult to articulate. Inferences about the relationship between the father's

response to diabetes and interactions in the family cannot be made due to insufficient data. However, these potential associations warrant exploration.

Conclusion

There is a glaring lack of research examining the paternal response to diabetes. Clinical judgements and interventions regarding the father's positive and negative responses to the diabetes and the diabetes care are not based on a systematic understanding of the processes experienced by fathers. In fact, the process by which the father assimilates care of a child with diabetes into his life could not be extrapolated from the literature. However, the research that has been done suggested that this process is multifaceted and related to internal and external factors. The apparent complexity of this process, therefore required a research approach that would address the integrative process qualitatively, from the father's perspective.

CHAPTER THREE

METHODOLOGY

Introduction

The research design and methodological decisions were directed by the purpose, and the nature of the proposed study. In the following chapter, the research methodology selected for this study and the implementation of the research design are presented. In the first section of the chapter, the methodological decisions are reviewed. The implementation of the research design is presented in the second section.

Methodological Decisions

In this section, an over-view of quantitative and qualitative research designs are presented. The considerations made during the selection of a research approach for this study are discussed. This section is concluded with a presentation of the characteristics of the research approach used in this study, the grounded theory approach.

Quantitative and Qualitative Research Designs

Nursing research may be conducted using a quantitative approach, a qualitative approach, or a combination of the two (Field & Morse, 1985). Quantitative and qualitative methods differ in their research philosophy, focus, and design.

Quantitative research supports a mechanistic and static view of reality. Objectivity, control, determination of causal relationships, and testing hypotheses are the basis of this deductive method (Polit & Hungler, 1987; Wilson, 1985). This method is most appropriate in research studies that seek to: determine cause and effect relationships; rigorously test hypotheses; or determine attitudes or practices of a large population (Polit & Hungler, 1987).

Qualitative research stresses a humanistic view. Control and manipulation of variables does not occur; instead, knowledge about the human experience is derived inductively by describing, explaining, and interpreting, informants' feelings, views, and actions (Leininger, 1985). This research is based on the underlying assumption that knowledge about humans can only be derived by studying individuals' perceptions of

themselves and their world (Leininger, 1985). This method is used to: describe a phenomena that there is little known about; generate hypotheses; illustrate the meaning of descriptions or relationships; understand relationships and causal processes; and develop theory (Polit & Hungler, 1987).

Selection of a Research Methodology

The type of research approach selected was determined by the purpose of the study and the specific research question. The main purpose of this research was to develop a beginning substantive theory describing the father of a child with diabetes. Specifically, the research asked: what is the process through which father's assimilate their child's diabetes into their lives? The purpose of this study, and the research question focused on: the interpretation, and discovery of experiences from the father's perspective; and the description of a multifaceted process. Therefore, a qualitative approach was determined to be an appropriate methodology for this study.

Three qualitative approaches were considered for

this study: ethnography, phenomenology, and grounded theory. Each method uses the researcher as an 'instrument' and strives to understand experiences from the informant's perspective; however, the origins and the focus of each method vary slightly (Field & Morse, 1985).

A review of these three approaches revealed that the grounded theory approach was the most appropriate method to address the research topic. This research approach reveals a basic psychosocial process, a central concept in the research question. In addition, the grounded theory approach provided a method for systematic data analysis and theory development. A description of the grounded theory approach is presented in the following section.

Grounded Theory Methodology

A grounded theory approach is characterized by three properties: a symbolic interactionist perspective, a systematic inductive and deductive logic, and a field research approach to data collection. These procedures promote the development of theory that reflects a basic psychosocial process.

The theoretical basis for the grounded theory approach is symbolic interactionism. An inductive, anti-reductionist, exploratory, and process oriented approach have been incorporated in the grounded theory research method (Chenitz & Swanson, 1986; Glaser & Strauss, 1967). Perceptions and personal meanings are explored, described, and eventually articulated in a grounded theory report.

The second characteristic of the grounded theory approach is the application of both inductive and deductive logic. Tentative hypotheses are derived, and verified during simultaneous and systematic data collection and analysis; this allows theory development that is captured, and tested, during the research process (Charmaz, 1983). Theory development occurs through the "constant comparative method" of data analysis and "theoretical sampling" (Glaser, 1978; Glaser & Strauss, 1967).

The constant comparative method refers to a continuous, evolving process of data analysis that occurs through the procedures of open coding, axial coding, and selective coding (Strauss, 1987; Strauss &

Corbin, 1990). In open coding, the data are compared, contrasted, conceptualized and categorized. The data are examined line by line and broken down into discrete incidents or concepts that are then examined for similarities and differences. Similar concepts are grouped together, and given a conceptual name called a category.

In the second analytical technique, axial coding, the data are put back together in a new form. Categories are developed by searching the data for properties of a category. Each category is specified in terms of four "subcategories": the conditions that give rise to it, the context in which it is embedded, the strategies by which it is handled, and the consequences of those strategies (Strauss & Corbin, 1990, p.97). Articulation of the four subcategories occurs through proposing tentative relationships between categories and subcategories, and reviewing the data to look for evidence, incidents, and events to support or refute the proposed relationship.

In the final phase of the analytical procedure, selective coding is used to identify the core category, or the central phenomenon of the theory. Analysis

becomes more abstract as all categories are related to the core category.

The analytical procedures of open coding, axial coding, and selective coding are promoted by three types of written memos or "notes": observational notes, methodological notes, and theoretical notes (Schatzman & Strauss, 1973). Observational notes are statements that reflect observations which are derived from watching and listening. Methodological notes are statements that reflect directions to oneself regarding the research process. Finally, theoretical notes represent deliberate, and thoughtful statements that identify and elaborate categories.

The constant comparative method is also supported by theoretical sampling. In theoretical sampling, incidents, not persons, are sampled; sampling is guided by the analysis and articulation of emerging theoretical concepts (Strauss & Corbin, 1990). During data analysis, concepts that have relevance to the evolving theory are identified. These concepts are further explored, or "sampled" in already collected data and in future interviews (Strauss & Corbin, 1990). This process of sampling concepts, promotes the

elicitation of additional data and the articulation of the concepts until "saturation" occurs.

The third characteristic of grounded theory is the reliance on a "field research" approach to data collection. The two field approaches frequently used in grounded theory are participant observation and interview (Chenitz & Swanson, 1986; Glaser, 1978; Stern, Allen, & Moxley, 1984; Strauss & Corbin, 1990).

"Participant observation" refers to data collection methods that rely on observation alone, or a combination of observation and questioning. This approach allows for the observation of non-reported behaviours, and for the verification of reported behaviours (Field & Morse, 1985).

The second field research approach used in grounded theory research is interviews. Interviewing may be used alone or to augment participant observation data. Although combining interviews and participant observation is recommended (Schatzman & Strauss, 1973), several researchers have conducted grounded theory studies using interviews alone (Bowers, 1987; Clements, Copeland & Loftus, 1990; Jordan, 1990; Olshansky,

1987). In grounded theory, the interview has been described as a "lengthy conversation" (Schatzman & Strauss, 1973) or "conversation with a purpose" (Lincoln & Guba, 1985). The conversational format of the interview reflects the naturalistic, and flexible data gathering approach characteristic in field research.

Swanson (1986) proposes that the interview in a grounded theory study must contain components of an open, unstructured interview and a guided, structured interview. This author suggests that the interviewer use a guide that contains a set of brief questions, an outline, or a theme for the interview; this interview guide changes with the changing focus of the research. However, this guide does not inhibit an open, exploratory approach. Swanson (1986) advises the researcher to always address the respondent's major concerns or viewpoint.

In summary, the grounded theory approach is characterized by three properties: a symbolic interactionist perspective, an inductive and deductive approach, and a field research approach. These

properties illuminate the grounded theory prospective: the development of theory, derived from qualitative data, that reflects the "discovery" of experiences from the respondent's perspective.

Research Design Implementation

The research design was qualitative, exploratory and descriptive in nature utilizing a grounded theory approach with a modified theoretical sampling strategy. Sampling was modified by focusing on the exploration of the father's experiences at least one year following his pre-adolescent child's diagnosis. The substantive area of study was the father, of a pre-adolescent child with diabetes, who was involved in the process of assimilating his child's diabetes into his life.

Participants

The theoretical "population" of interest was fathers who lived with their child who had IDDM. However, this population was limited in order to place some boundaries around the area of study to allow reasonable possibility of saturation of categories. The age of the child was restricted to less than 13 years. The parental involvement in care-taking changes during adolescence; gradually the parents relinquish the control and responsibility for the diabetes to their child (Ingersoll, Orr, Herrold, & Golden, 1986).

An assumption of this study was that this process of transferring care involves a separate "integrative" process; therefore, it was not explored in this study. An additional restriction involved the duration of the diabetes. Resolution of psychologic responses typically occurs during the first year following diagnosis (Kovacs et al, 1985; Kovacs, Iyengar, Goldston, Obrosky, Stewart, & Marsh, 1990; Tarnow & Tomlinson, 1978); therefore, a second assumption of this research was that conducting interviews after this "first year" would allow exploration of the father's experiences without being complicated by the psychological response to diagnosis. Consistent with these limitations, respondents who met the following criteria were admitted into the study:

1. the father of a child less than 13 years of age who has had IDDM more than one year,
2. capable of reading, writing, and speaking English,
3. living with his child who has IDDM,
4. available by telephone in order to arrange an interview,
5. accessible by car.

A convenience sample was elicited from the Canadian Diabetes Association's (CDA) regional office in Vancouver, British Columbia (see Appendix A & B). The respondents were recruited from the CDA's membership mailing list. Those families who had a diabetic child less than 13 years of age were sent a recruitment letter that outlined the purpose and method of the study (see Appendix C). A total of 110 letters were sent to families who had a diabetic child less than 13 years of age; children who had diabetes less than one year may have been included in this mailing.

Thirteen respondents who were interested in participating in the study called the researcher. Using prepared guidelines (see Appendix D), the researcher explained the study to the potential respondent. Ten respondents, who met the criteria, were interviewed at a later date.

Research Instruments

The selection of the research instruments was influenced by: the purpose and nature of the research; a preliminary review of the literature; and the theoretical basis of a grounded theory approach.

The research instruments were structured to address five general questions:

1. How does the father describe the experience of being a parent of a child with diabetes?
2. What are the father's responses to his child's diabetes and care?
3. How do the father's responses to the diabetes influence his interactions inside and outside the family?
4. How do the father's responses to his child's diabetes change over time?
5. How do the responses of others influence the father?

Two research approaches were considered: participant observation, and interview. A support group setting and the home setting were considered as potential sites for participant observation. However, fathers of children with diabetes do not consistently participate in any "group" that could be observed. Observation of individual fathers in their home was ruled out due to practical concerns regarding the time and expense involved in this approach. Therefore, interviewing was selected as the research instrument.

Interview Guide

An interview guide was developed to reflect Swanson's (1986) formal, unstructured interview format. Appropriateness of the interview guide was assessed during a pilot interview which was included in the data analysis. The interview guides were also critiqued in methodological memos.

The interview consisted of four phases: 1) a social-talk phase characterized by general conversation; 2) a "warm-up" phase involving introductory comments regarding the research and the introduction of a general question; 3) a guided conversation phase characterized by general questions and probing; and 4) a closing phase where the interview was ended but consent for future contact was obtained.

Specific interview questions were directed at gaining an understanding of the father's experiences with his child's diabetes. The opening questions were broad and general in nature. This type of question promoted the comfort of the respondent and introduced a major theme. Questions in the remainder of the interview were also general in nature to allow the respondent to share personal experiences. Four types

of probes were used throughout the interview: 1) chronology (...when was that?); 2) detail (can you tell me more about that?); 3) clarification (I am not sure what you mean; are you saying...?); and 4) explanation (how did that happen?) (Schatzman & Strauss, 1973, p. 74). Other questioning techniques recommended by Schatzman and Strauss (1973) were used and included: the use of hypothetical questions (if you met a father on the street, what would you say?); posing the ideal (if this was an ideal world, what would a father receive for support?); and testing propositions (other fathers have told me ... what do you think about that?).

The interview guide was modified several times during the research process due to theoretical sampling. Concepts that emerged during data analysis were theoretically sampled in subsequent interviews; the nature of the questions changed as the emerging theory was developed and refined. The interview guides used in the study are presented in Appendix E.

Demographic Tool

Demographic data were collected in order to describe the sample (see Appendix F). Previous

research has shown that sociocultural and economic factors influence the illness meaning and illness management (Anderson & Chung, 1989; Glatzer, Amir, Gil, Karp, & Laron, 1982; Kovacs et al, 1985; Kovacs et al., 1990). However, according to grounded theory research, these variables were not considered until the respondents' discussions indicated that they were important.

Time

The study was retrospective and examined the fathers' experiences with their child from diagnosis to the time of the interview. The duration of the child's diabetes varied from three to nine years with a mean duration of 5.9 years. This retrospective focus allowed the elicitation of data regarding process.

Setting

The interviews were conducted in one of two settings: the work setting, or the home setting. Selection of the setting was based on the father's preference.

Method of Data Collection

Data were collected through ten in-depth, audio-taped interviews that lasted one and a-half to two hours. The interviews were initiated with a verbal description of the study, the presentation of a written explanation of the study (Appendix D), and signing of the consent (Appendix G). Demographic data were then collected and the interview was initiated.

The interview guide was used to provide a focus for the interview; however, in situations where the respondent's discussion digressed from the guide, strict adherence was not practised. During these situations, probes and follow-up questions were introduced in order to encourage the respondent's full description of his experiences. This approach did not limit the respondent's discussion to interviewer selected topics but rather encouraged the sharing of personal meanings, experiences, and processes.

The content of each interview gave form and substance to the next interview. A theoretical sampling approach was used to direct the sampling. Rather than the fathers themselves, the units of analysis were the fathers' verbal reports of their

experiences related to their child's diabetes. As concepts began to emerge in the data, respondents were sampled to elicit additional data in order to expand or alter the categories. Conscious decisions were made as to what concepts were to be attended to, and how additional information might be gathered. Previous interviews were re-analyzed to develop emerging categories and subsequent interviews were focused and directed to category development.

Method of Data Analysis

Data collection and data analysis occurred concurrently as transcribed audio tapes were coded and reviewed using the constant comparative method of data analysis. The goal of the data analysis was to discover the core variable, that is, the basic psychosocial process involved in the father's assimilation of his child's diabetes. This phase of the research occurred over an eight month period.

Four procedures were used to facilitate data analysis: 1) transcription procedures, 2) organizational procedures, 3) a concurrent review of the literature, and 4) analytical procedures.

Transcription Procedures

Transcription procedures involved the transcription of the interview immediately following the interview. Audio tapes were transcribed, verbatim, onto a computer using the WordPerfect program. These notes were then transferred to a qualitative analysis software program titled The Ethnograph (Seidel, Kjolseth & Seymour, 1988). Immediate transcription allowed for prompt analysis which is consistent with the constant comparative method of data analysis.

Organizational Procedures

These procedures were used in an effort to arrange the interview materials, transcribed tapes, and analytical memos. The first organizational procedure involved the development of a chart that included the identifying information of the respondents. The chart included the date of the interview, the time, the setting, and contact information. This information was used when a follow-up contact was required.

The second organizational procedure consisted of a written summary of each interview. This summary included: the case number; the setting; demographic data; the father's level of involvement in his child's

care; the main "storyline"; and the researcher's impression of the interview, the father's role, and the factors influencing the father's experiences with his child. This summary assisted the researcher in accessing the appropriate interview during analysis.

The third organizational procedure involved notations regarding theoretical sampling and the resultant changes in the interview guide. A flow chart identified which interview guide had been used with each case and specified when the interview guide was changed in order to sample theoretically an emerging theme. This flow chart reflected decisions made in methodological notes and theoretical notes.

Review of the Literature

A review of the literature was conducted during the later stages of data analysis. The use of the literature was consistent with the grounded theory approach. Once categories were identified, the literature was reviewed to determine if the researcher-identified concepts had been previously identified and described (Strauss & Corbin, 1990). For example, theoretical literature reviewed during analysis included role theory, grief and loss, chronic illness,

and skills acquisition.

Analytical Procedures

These procedures were numerous and complex. Analysis was facilitated by the use of Ethnograph (Seidel et al., 1988) which allowed for the input, and retrieval, of coded segments of data. Open coding, axial coding, and selective coding were also used. The data analysis proceeded through five phases that parallel Corbin's (1986) interpretation of the constant comparative method (Glaser & Strauss, 1967).

1. Phase 1: During the fist phase, the data were read line by line. Incidents and facts were underlined and codes were written in the margins. The analysis, at this time, focused on searching for general experiences of the father. In this phase, codes were descriptive and lacked analytical elements.

Analytical memos in the form of observational, methodological, and theoretical notes were initiated. In the early phases, these notes were disjointed and reflected early notions regarding relationships, themes, and analytical strategies.

Through the process of early coding and memoing, patterns in the data began to emerge and beginning

categories were identified. For example, early categories included emotional responses, learning/knowing, organizing, and role finding.

2. Phase 2: Building, densifying, and saturating the categories occurred during this phase. During this phase, questioning became more directed in an effort to expand and describe each category. The data were examined and re-examined repeatedly to compare and contrast incidents from respondent to respondent. Consistencies and inconsistencies were noted and relationships were speculated.

Earlier descriptive codes were reviewed and collapsed into analytical code words that reflected a concept rather than a specific incident. For example, the code "response to diagnosis" was re-coded as "grief" or "taking on responsibility". These codes were further reviewed and compared and organized under categories that reflected processes. For example, the code "grief" was considered under the early category of "emotional response".

In this phase, the memos were more detailed, comparative, and analytical. The theoretical notes described early categories and their properties while

methodological notes outlined theoretical sampling strategies.

3. Phase 3: During this phase the categories and subcategories were further conceptualized and relationships between categories were identified. The conceptualization of the categories was facilitated by reviewing the data for subcategories, or the conditions, contexts, strategies and consequences. Transcribed interviews were reviewed and several questions were asked: how are the categories related and connected; what are the characteristics of the categories; and what are the consistencies and inconsistencies in the data? Tentative relationships were proposed. Interviews became more formal and systematic as tentative hypotheses were validated or qualified.

Memos were more analytical and reflected the articulation of saturated categories, tentative hypotheses, and verification processes. The categories of emotional work, cognitive work, role work, and restructuring work were identified in theoretical memos during this phase of analysis.

4. Phase 4: During this phase, the categories were

pulled together around a core category. Three approaches were used: 1) each interview was reviewed for the main "storyline"; 2) each category was speculated to be the core category while the question was asked: does this category explain the total process and can all other categories be subsumed under this category?; and 3) two respondents were re-interviewed in order to validate the researcher's interpretations of the data and the core category.

5. Phase 5: During this phase, refinement of the theory occurred. This was accomplished by laying out the theory in diagrams and ensuring that categories and subcategories were specified, dense, and supported by the data. Collapsing of categories also occurred. For example, a category titled "restructuring work" was assimilated into a role work strategy.

The five phases of analysis were not linear but rather continuous and integrative. Codes and categories were refined several times regardless of the "phase" of analysis. Memo development and diagramming grew in depth and detail as categories emerged.

In summary, with the exception of modifications

made in sampling, the implementation of the research design of the study was consistent with the grounded theory approach. Within the boundaries of the study, the method of data collection and data analysis reflected the grounded theory approache to theoretical sampling and the constant comparative method. Hypotheses were not developed a priori but rather emerged during the data analysis. The data, and the respondents validated and refined the hypotheses and the developing theory.

Measures to Enhance Rigor

Several authors have argued that the rigor of qualitative studies cannot be assessed using the criteria established for quantitative studies because of dissimilarities in the goals and methods of these two types of research (Field & Morse, 1985; Leininger, 1985; Lincoln & Guba, 1985; Sandelowski, 1986; Strauss & Corbin, 1990; Yonge & Stewin, 1988). Some authors have abandoned quantitative measures of rigor and developed approaches more consistent with the qualitative approach. Lincoln and Guba (1985) use the term "trustworthiness" to judge the merit of a study.

These authors' state that if a study is deemed trustworthy, its findings are worth considering.

Lincoln and Guba's (1985) articulation of trustworthiness, and Sandelowski's (1986) interpretation of the work of Guba and Lincoln (1981), were used during this research. These authors' submit four criteria that can be applied when judging a study: "truth value", "applicability", "consistency", and "neutrality". Each of these criteria were considered during the planning and implementation of the study.

The first criterion, "truth value" or credibility, is synonymous with internal validity. Truth value is achieved when the research presents true and faithful descriptions and interpretations of the phenomena under study (Lincoln & Guba, 1985). Other readers are able to recognize the descriptions as being "true".

The major threat to truth value is "going native", that is, the researcher is unable to separate his/her own experiences from those of the respondents (Sandelowski, 1986). An additional threat to the truth value is insufficient time and analysis which impedes a truthful understanding of the "culture" and experiences of the respondents (Lincoln & Guba, 1985).

Lincoln and Guba (1985) suggest several strategies to promote the truth value or credibility of research findings. Consistent with their recommendations, the truth value in this study was promoted by prolonged contact, peer debriefing, persistent observation, and member checks. First, the duration of the researcher's involvement with fathers of children with diabetes promoted the truth value of the study. Data collection and analysis occurred over a eight month period; the researcher also had five years of experience working with families of children with diabetes. This experience enhanced the researcher's understanding of the terminology, "routines", and experiences related to diabetes. However, this "knowledge" may have increased the researcher's risk of "going native" and "being blind" to some experiences. This risk was acknowledged and addressed through peer debriefing. The researcher's advisor reviewed, and discussed each interview and the analytical memos. These discussions stimulated problem solving, minimized distortion of the data, and increased the researcher's sensitivity to the data. Informal discussions with a nursing colleague unfamiliar with the research area, also assisted the

researcher in explicating the data.

The technique of persistent observation was also used to address the truth value of the study. Recurrent themes in the data were attended to until "saturation" occurred. Code and re-code procedures were conducted throughout data collection and data analysis in order to ensure that the fathers' experiences were captured and thoroughly explicated.

Finally, member checks were used to promote the credibility of the study. The nature of the constant comparative method allowed for validation of hypotheses throughout the research process. In addition to this on-going validation, two respondents were re-interviewed following completion of data collection and data analysis. The purpose of these interviews was to ensure that the themes portrayed in the theory were recognizable to the informants. In each case, the processes articulated in the theory were explained and the respondents were given the opportunity to critique the theory.

The second criteria, applicability or transferability, is similar to generalizability. Findings are applicable when they are transferable to

other subjects, settings, and contexts. The findings "fit" the data from which they were derived and contexts outside of the study situation (Sandelowski, 1986).

The applicability of research findings is threatened by "elite bias" and "holistic fallacy" (Sandelowski, 1986). Elite bias refers to the reliance on respondents who are articulate, accessible, or high-status members of their groups; holistic fallacy refers to presenting the data in a more congruent manner then they are (Sandelowski, 1986, p. 32).

In this study, these threats to applicability were acknowledged and addressed. The sample was clearly described in order to ensure that the findings could be knowledgeably transferred to similar contextual areas. The "fit" of the data was also ensured by the constant comparative method of data analysis and consistent support of the theoretical statements with objective data derived from the interviews.

The third criterion, consistency or dependability, is congruent with the replicability of the study (Sandelowski, 1986). The aim in consistency is to determine whether the findings of an inquiry could be

repeated with similar subjects in a similar situation (Lincoln & Guba, 1985). A study meets this criterion when the research findings are auditable; that is, a second researcher following the original investigators' research process would arrive at similar, or non-contradictory findings (Lincoln & Guba, 1985; Sandelowski, 1986).

In this study, this criterion was addressed by outlining the decisions, interpretations, and procedures of the study in sufficient detail so that another researcher could follow the research process. Changes made in interview guide were documented and revised interview guides were recorded.

The fourth criterion, neutrality or confirmability, refers to freedom from bias. Neutrality is achieved when the criteria of truth value, applicability, and consistency are met. In this study, the criterion of neutrality was addressed by establishing the truth value, applicability, and consistency as already described.

In summary, several procedures were instituted in order to enhance the trustworthiness of the study. These measures included: prolonged contact, peer

debriefing, persistent observation, member checking, use of the constant comparative method, describing the sample, and clear descriptions of the research decisions and method.

Ethical Considerations

Ethical issues were considered during all phases of the research process. During the planning phase, ethical implications of the study were addressed and outlined in a research proposal. This proposal was submitted to, and approved by, the Ethical Review Committee of the University of Manitoba prior to the institution of the research (see Appendix H).

Ethical issues that were addressed during the implementation and writing phases of the research process were: 1) informed consent, 2) protection of the participants, and 3) confidentiality.

Informed Consent

All participants volunteered to participate in the study. Informed consent was achieved by ensuring the respondents knew and understood the nature of the study. This issue was addressed by: 1) providing the

respondents with written and verbal explanations of the study (Appendix D); and 2) the review and signing of a consent form (Appendix G). It was emphasized that participation was voluntary and the respondent could refuse to answer specific questions, and/or withdraw from the study at any time.

Protection of the Participants

Efforts were made to protect the psychosocial well-being of the respondents. The participants well-being may have been influenced by aspects of the interview process itself, the recall of personal experiences, or concerns regarding the Canadian Diabetes Association's (CDA) role.

Protection of the participants during the interview itself was assured by explaining, in advance, that the interview could be conducted in one or two sessions, and that it would last one and a-half to two hours. Other measures to promote the respondents' comfort included: meeting the respondent at a location of his choice; offering to stop the interview or turn the tape recorder off at the respondent's request; and allowing the respondent to refuse to answer specific questions.

A second ethical consideration involved the respondent's response to the research questions. Because the interview questions, and the exploration of feelings, may have caused the recall of previously painful events, the respondent's non-verbal and verbal communications were monitored throughout the interview. If the respondent appeared to be upset or experiencing difficulty with specific questions, he was given the opportunity to stop, to continue talking, or turn off the tape recorder.

A third ethical issue involved the respondents potential concern regarding the role of the CDA in the research. The respondents were assured that their names were not released to the agency and that their participation in the study would not influence their child's health care.

Confidentiality

Measures were taken to ensure that information obtained during the study was handled in a way that ensured the confidentiality and anonymity of the participants. These measures, outlined in the consent form (Appendix G) and explanations (Appendix D), were adhered to.

All respondents gave permission for the publication of the study through their informed consent. Care was taken during the writing of the study results. Situations were altered slightly, without significantly changing the data, in order to protect the respondent's anonymity.

Limitations of the Study

Limitations of the study were as follows:

1. The demographic characteristics of the respondents in the study are not characteristics of all fathers who have a child with IDDM. Therefore, it is possible that the experiences of fathers with different sociodemographic characteristics may not fit the findings of this study.
2. Because of boundaries placed on the recruitment of respondents, the findings of this study only reflect the experiences of fathers of preadolescent children.
3. The retrospective design of the study may have resulted in findings that are limited by problems of the father's recall of experiences during the first years of his child's diabetes.

Conclusion

This chapter addressed the methodological decisions and the research design used to study the experiences of fathers of children with IDDM. Quantitative and qualitative research methods were briefly compared and contrasted. The grounded theory approach selected for this study was described; rationale for this selection was provided. The specific design of the study was presented and measures to enhance the rigor of the study were outlined. Finally, ethical issues considered during the study, and limitations of the study, were presented.

CHAPTER FOUR
FINDINGS

Introduction

In this chapter, the findings of the qualitative study examining the responses and experiences of fathers who have a child with IDDM are presented. In the first section, a description of the sample is presented. The findings of the qualitative data analysis are elaborated in the second section.

Description of the Sample

Ten fathers participated in the study; all were married with two to four children. In each family, only one child had diabetes. Nine of the ten fathers were Caucasian. In general, the fathers in the sample represented an articulate, educated, middle to upper-middle class group. Eighty percent of the fathers held a college diploma or an university degree; fifty percent were employed in professional status occupations. Seventy percent of the mothers also had college diplomas or a university degree; fifty percent had been employed in professional status occupations at some time during their careers. At the time of the

interviews, five mothers were homemakers. The remaining five mothers worked outside of the home; however, only one was employed full time. All of the children with diabetes were diagnosed in their preschool years; nine of the ten children were school-aged at the time of the interview. Demographic data is presented in Table 1.

TABLE 1: DEMOGRAPHIC CHARACTERISTICS

FATHER CHARACTERISTICS:

CURRENT AGE
mean 40.7 yrs.
range 34-49 yrs.

EDUCATION

PhD	2
Masters	1
Degree	3
Diploma	2
Grade 12	2

CURRENT OCCUPATION

Professional	5
Service Sector	3
Labourer	1
Self Employed	1

MOTHER CHARACTERISTICS:

CURRENT AGE
mean 39.3 yrs.
range 32-48 yrs.

EDUCATION

PhD	0
Masters	1
Degree	4
Diploma	2
Grade 12	3

CURRENT OCCUPATION

Professional	3
Secretarial	1
Unskilled	1
Homemaker	5

CHILD CHARACTERISTICS:

CURRENT AGE
mean 8.8 yrs.
range 5-11 yrs.

SEX

Male	6
Female	4

AGE AT DIAGNOSIS
mean 3 yrs.
range 1.5-5 yrs

DURATION OF DIABETES
mean 5.9 yrs.
range 3-9 yrs.

SIBLING CHARACTERISTICS:

CURRENT AGE
mean 9.3 yrs.
range 1-26 yrs.

Findings: The Work of Integrating Diabetes

The qualitative data analysis led to the development of a beginning process theory titled: Integrating Diabetes into Everyday Life: The Experiences of Fathers. This theory describes the processes through which a father assimilates his child's diabetes into all spheres of his life. "Integrating" is accomplished through the father's use of energy to achieve three types of "work": emotional work, role work, and cognitive work. This "energy" refers to the active and intense use of physical, emotional, and intellectual effort to achieve an objective or produce change. In this section, a detailed description of emotional work, role work, and cognitive work is outlined. This discussion includes the properties or attributes of the work, the strategies used to handle the work, and the primary condition that gives rise to the work. Throughout this chapter excerpts from the transcripts are presented to illustrate the findings.

The Work of Integrating: Emotional Work

The diagnosis, and resultant care, of childhood diabetes challenges the father to cope with the stress and uncertainty of a chronic illness, the daily diabetes care demands, and the changes that the diabetes causes in his lifestyle. Emotional work refers to the father's awareness, and use of energy to acknowledge the diabetes and adapt to its implications. The properties, the strategies used, and the primary influencing condition of emotional work are presented.

Properties of Emotional Work

The emotional work of the father was characterized by two related properties: acknowledging the reality of diabetes; and dealing with unrelenting worry. Each of these processes reflected the father's emotional efforts to acknowledge and adapt to the diabetes and its implications.

Acknowledging the reality of diabetes.

One component of emotional work was characterized by a process of acknowledging the reality of the diagnosis, and the implications of childhood diabetes. This process was depicted in four phases: reacting to

the diagnosis; growing realization; taking on responsibility; and reaching an accepted-reality. The fathers advanced through these phases in a progressive manner or fluctuated between phases. Progression through the phases was either complete or incomplete.

i) reacting to the diagnosis:

Each father presented his own unique response as he was confronted with the diagnosis of diabetes. Most fathers (n=9) experienced an intense emotional feeling when their child was diagnosed with diabetes. The fathers' responses were characterized by one, or two, of the following responses: shock and disbelief (n=5), a feeling of emotional upset (n=3), resentment and anger (n=1), and sadness and guilt (n=2). One father reported no awareness of an intense emotional response.

A temporary sense of shock and disbelief was the most frequent response (n=5). "Its like being shot in the head with a gun - total numbness and sort of like why me, what did I do wrong?". Of these five fathers, three reported that this sense of shock and disbelief was temporary and eventually replaced by a sense of acceptance. The remaining two fathers reported that their feelings of shock and disbelief were followed by

more persistent emotions. One father described a sense of sadness and guilt "Where does it come from - is it my fault?". A second father described prolonged anger and resentment: "I really had trouble accepting ... That really pissed [sic] me off! I mean you know, you are given this ...". Other fathers' predominant emotion was that of emotional upset accompanied by a sense of relief (n=3). "I was upset ... but I felt good - at least that we could treat him and make him less sick".

The predominant reaction of one father was a pervasive feeling of guilt and sadness.

> I always felt so cold and empty ... This guilt feeling - that in some way, shape, or form, I was accountable. I was being punished or I had done something that caused my child to have this affliction or condition.

Finally, one father, who had difficulty with emotional work, expressed no awareness of an intense emotional response, but rather a denial of the severity of the illness and an immediate reality orientation. This father stated: "I was thinking that I don't want to make a big deal out of this thing; maybe the easiest way to accept it is to just get on with it".

In summary, the father's reaction to the diabetes was individualized. In most cases, the father's reaction was characterized by an awareness of an intense, emotional feeling. The two predominant responses were: shock and disbelief; and a sense of upset but relief.

ii) growing realization:

As a result of the hospital experience and education, the father's reactions to the diagnosis were accompanied by a growing realization of the implications of diabetes. Within days of the diagnosis, the father became increasingly aware of the significance of diabetes in terms of his child's health and the family's responsibility for the diabetes care. For most fathers, this growing realization engendered feelings of being overwhelmed and responsible.

> It was overwhelming. I thought: 'God, I don't know, and I thought I knew, and I don't. I've got to learn all of this and everything is interrelated to everything else - and its my kid and he is broke, and I'm part of what happens to keep him going because you can't fix this thing; all you can do is maintain it.

A realization of losses was occurring concurrently. The diabetes imposed restrictions that

led to a loss of freedom for the father; there was also a growing realization that there may be losses related to the child's health and future.

> I am a creative, spontaneous type person, and you know, you lose all that...you don't have that sort of flexibility in your life. And I wonder what the impact of that type of element on his personality will be ... There is the sadness; you feel sorry for your child because you want your child to be the best they can be.

To summarize, the phase of growing realization was reflected in the father's increasing awareness of the implications of the diabetes. This realization was exhibited in feelings of responsibility and loss, and a sense of being overwhelmed.

iii) taking on responsibility:

During the third phase, the father took on some of the responsibility inherent in diabetes care. Earlier emotional responses continued; however, the father began to be active in his attempts to gain control of the diabetes.

> No one else is going to do it, and we had to show a little bit of responsibility, so we sort of threw ourselves into that right away.
>
> And it was up to us to find out as much about diabetes as we could, and the complications of diabetes, so that we could help him lead a more normal life. I guess that is just our feeling of responsibility - what our job was.

This phase of taking on responsibility marked the father's movement toward active acknowledgement of the diabetes. The father continued to express growing awareness of the implications of diabetes; however, he also initiated some form of active effort in order to gain a sense of control.

iv) reaching an accepted-reality:

In the final phase, accepted-reality, the father had acknowledged the diabetes and its related care. The father accepted the diabetes as part of his child and his life; he was realistic about the challenges that the diabetes presents. One father's comment reflected this blending of acceptance with the reality of diabetes: "I think I accept the diabetes and accept the battle that the child is going to have with the diabetes for the rest of his life". A second father's comments further illustrated the phase of accepted-reality: "acceptance is not like an end-stage; its like you are moved to a different level - more like reconciled to what the diabetes means".

Accepted-reality was the final phase of the father's efforts to acknowledge the diabetes. In this phase, the father adopted a reality-based sense of

resolution regarding his child's diabetes. This sense of resolution was not permanent; it changed as the father's perceptions of the child's needs changed. Some fathers left this phase and returned to earlier phases of emotional work as they were challenged to acknowledge "new" aspects of the diabetes such as hypogylcemic seizures or diabetic ketoacidosis.

In summary, one characteristic of the father's emotional work was acknowledging the diabetes. The fathers' work in this phase was depicted by: reacting to the diagnosis; developing a growing realization of the diabetes; taking on responsibility for the diabetes; and finally, reaching an accepted-reality. These four phases were over-lapping, and inter-dependent; the father's time in, and movement through, each phase was individualized. The work of acknowledging the reality of diabetes was dependent on the resolution of each of the phases. Difficulty with one phase may have inhibited the resolution of the subsequent phase thereby hindering the father's emotional work.

Dealing with unrelenting worry.

In addition to acknowledging the diabetes, the father also used emotional energy to deal with the unrelenting worry of diabetes. In this component of emotional work, the father used energy to accommodate to three types of "worry": unrelenting responsibility for the child with diabetes; unrelenting uncertainty; and unrelenting family concerns.

i) unrelenting responsibility:

Daily, the father of a child with diabetes shared the responsibility for: maintaining the child's schedule, ensuring that the diabetes regime was adhered to, and monitoring the child's health. This responsibility was present 24 hours per day, every day. Whether the child was with the family or not, the parents were ultimately responsible for ensuring that the child with diabetes was cared for at all times.

> ...up to 4 finger tests, 6 meals, 2 injections. 'If you are going to do any extra running or playing son, here is some extra food; drink this apple juice; eat some starch. OK, what do you mean everyone stop playing because he is still eating?' You know, worrying constantly.

The degree of the father's unrelenting responsibility depended on the role that he had taken

on in the care of his child. Fathers who were more active had more unrelenting responsibility than those fathers who were less active.

ii. unrelenting uncertainty:

The father struggled with a continuous sense of uncertainty related to himself, the child's health, and the future. The father experienced worry and concern regarding his own skill in caring for the child.

> It was the stress of getting it right and the stress of getting it on time and the feeling of responsibility if the sugars aren't - if they were high. You sort of are figuring 'what did I do wrong, or what could I have done differently' - you know, to keep the sugars down.

Worry about the child's health was unrelenting. There was the ever-present potential for hypoglycaemia, hyperglycaemia, or ketoacidosis. This type of worry was more frequent when the child was not within the care of either parent. Common childhood activities, such as going to a movie, were worrying for the father because "you have to fight down the temptation to stand outside the theatre door".

Social situations were often more stressful than relaxing for the father who worried that alternative care-givers may not provide the care that the child

required. "Its hard to call on people ... and you have got to worry about the needles, and more importantly, the food and the exercise, all day long".

There was also uncertainty and worry regarding the future. The father worried about the threat of the long term complications of diabetes. One father's comment regarding blindness exemplified this worry and uncertainty: "if he were blind at 20 ... you have got a chronically ill adult child. That would be very hard on my wife and I". This type worry was continuous; the threat of complications was always present.

iii. unrelenting family concerns:

The father also worried about his ability to attend to all family members due to the numerous, and often competing demands, from his wife, children, and career. Most fathers (n=9) worried about the effect the diabetes had on the wife. One father's comments demonstrated concerns about potential problems that the wife may experience: "I think that it is also important for the wife to not take the full load of the diabetes ... it would just be very stressful". A second father's comments illustrated the worry that the father felt when problems actually occurred: "My wife

got depressed at times so that was another problem to worry about".

Fathers (n=10) also encountered unrelenting concerns about their children's responses to the diabetes. The father worried that his well siblings' needs may not be met; at the same time he felt compelled to attend to the diabetic child's special needs. One father discussed the challenge of balancing all of his children's needs:

> The others [siblings] are a bit resentful because she sort of gets some special attention, although we try and minimize that. But sometimes we have to accommodate her ... We have to make sure her needs are met; we just have no other option.

The diabetic child's response to his/her diabetes was also upsetting and worrying for the father. "He would say 'I wish I wasn't diabetic' - and we would feel bad about that". "He doesn't express his feelings at all. Its hard; it is very difficult to determine how he regards his diabetes".

Finally, for some fathers (n=5) there was unrelenting worry about the conflict between meeting the family's needs while continuing to function effectively in a career. "There is this horrible

tension in my life between my career and my home because I don't do either well". Fathers who desired an active role with their child were more prone to this type of worry.

In summary, the second component of emotional work was characterized by dealing with unrelenting worry. The properties of this work included unrelenting responsibility, unrelenting uncertainty, and unrelenting family responsibilities. Dealing with unrelenting worry was a continuous process characterized by the father's emotional efforts to adjust to the worries associated with his child's diabetes. Unrelenting worry decreased, but never disappeared. Similar to the emotional work in acknowledging the reality of diabetes, the degree of the father's unrelenting worry was individualized. The father's worry related to his specific family circumstances and his involvement in his child's care.

Strategies in Emotional Work

The father managed the emotional work of diabetes by using five "strategies". These strategies were

reflected in the father's actions, and interactions with himself, and others as he attempted to manage two tasks: acknowledging the reality of diabetes; and dealing with the unrelenting worries of diabetes. Each strategy was used primarily to manage one of these two tasks. These strategies included: personalizing; reality-reasoning; managing; normalizing; and sharing.

Personalizing.

Personalizing is defined as the father's development of his own private view of the diabetes and/or the diabetes care-taking tasks. The father perceived his child's diabetes in a way that was congruent with his general perceptions of his life and his child. This strategy allowed the father to find meaning in the diabetes and thereby cope with the emotional reactions associated with the diagnosis. One father's discussion of his struggle to acknowledge his child's diabetes reflected this strategy:

> Its surprising how long it took me to come to my own reality within myself that it is the same genes that give the diabetes, but it is those same genes that made him himself - so you take the good with the bad.

Personalizing could also involve labelling the diabetes and the care-taking tasks in positive terms. One

father commented that "every time you give him insulin, you are giving him health". Another father stated that "its not that bad, its a manageable condition; its more like having a pacemaker because the system needs an external stimulation".

All fathers used the personalizing strategy; however, this personalizing either advanced or hindered the father's emotional work. Personalizing through the use of negative attributes hindered emotional work. For example, a father who experienced difficulty with emotional work personalized the diabetes as a helpless situation. He commented "there is nothing you can do, you just carry on". This type of personalizing may have prolonged this father's emotional work.

Reality-reasoning.

A second emotional work strategy was reality-reasoning. Reality-reasoning is defined as the use of intellectual and rational cognitions. For many fathers, (n=6) a reality-reasoning approach was useful in other aspects of their lives; they simply transferred this approach to their emotional work. One father's comment portrayed the transference of this approach to his child's diabetes:

> I grew up believing that you have got to play with the cards you are dealt ...its [the diabetes] reality; accept it; get on with the program; get moving; make adjustments; adapt; blend it in; cope; compensate. But get on with everything else ...because you have got to continue.

In reality-reasoning the father's perceptions of his situation and the diabetes were based on the father's logical view of his reality. One father's reflection of his family responsibilities illustrated this approach:

> You have other things; you have to look after the other children. You know, if you are the breadwinner, you have to go out to work ... you are not going to achieve anything by sitting there being depressed anyway.

Other fathers used reality-reasoning to cope with the emotional aspects of the diabetes care. One father stated:

> I try to interject as much reality as I can ... its part of life; its just like brushing your teeth, polishing your shoes, shovelling your sidewalk. ... If you just deal with it as any other physical need, then probably its a lot easier to cope with.

Finally, most fathers'(n=9) reality-reasoning was also characterized by a positive approach. Positive reality-reasoning allowed the fathers to view the diabetes rationally, and therefore minimized the emotional impact. One father's statement reflected

this positive reality-reasoning:

> I would be positive ... I try to take that outlook in life. I try to turn it into a positive. Its unfortunate that you have it, but what are you going to do with it? You have to deal with it.

Reality-reasoning was used by all fathers. However, fathers who relied on a rational approach in other aspects of their life were more likely to use this approach more frequently in the course of their emotional work.

Managing.

A third strategy, managing, is defined as the father's efforts to gain a personal sense of mastery or control over the diabetes. Managing strategies were developed through knowledge and involvement in care. Use of managing strategies minimized unrelenting worry and promoted taking-on responsibility for the diabetes. One father's statement illustrated the benefits of managing strategies in emotional work: "You just deal with it every day ... and the more you find out about, you find out its not the biggest deal".

Managing strategies were also developed by handling, and feeling prepared for emergencies. Often this type of managing could not occur until the father

had experienced a crisis related to the diabetes. Once the father had dealt with this crisis, a stronger sense of control emerged and worry was lessened.

The use of managing strategies was related to the father's involvement in care and the extent of the father's knowledge. The more involved and knowledgeable the father was, the more regular was his use of managing strategies.

Normalizing.

The fourth emotional work strategy was normalizing. Normalizing is defined as the father's efforts to minimize the risks and restrictions of diabetes and focus on characteristics of the child that do not represent the illness. By using this strategy, the child was viewed as more normal than abnormal. There were three styles of normalizing: comparing oneself to others; selective attention to normal attributes; and altering perceptions. Normalizing strategies were aligned with reality-reasoning strategies; in normalizing, the father used a reasoning approach to structure his view of his child as normal rather than abnormal.

First, the father attempted to normalize the

diabetes by comparing himself to others who he perceived as less fortunate. This approach of comparing the diabetes to other conditions was commonly used during the initial diagnostic period. At this time the father was confronted with other ill children and viewing his child as more fortunate, assisted him with his own emotional reactions.

A second normalizing approach that the father used was selectively attending to 'normal' aspects of the child. The father perceived his child as normal by focusing on characteristics that he considered exemplars of health such as the child's energy and fitness. The diabetes could not be seen and, therefore, emphasis on "healthy" characteristics was relatively easy. This tendency to emphasize normal characteristics was used by all fathers; however, it was frequently used by fathers who did not use the cognitive based strategies (reality-reasoning, managing) regularly.

A third normalizing approach was actively adjusting perceptions, and the diabetes routine, in order to present a 'normal' life for the child. The father attempted to re-frame situations in order to

minimize, and negate, the impact of diabetes. For example, one father stated:

> what he does or doesn't do is not determined by the diabetes, but maybe when he does it, or what he has to eat, will be determined by his diabetes. We do not allow the diabetes to control what he does.

This mental re-framing of the diabetes was accompanied by conscious and deliberate efforts to promote the child's unrestricted participation in 'normal' activities.

The fathers who used this particular normalizing approach also used other cognitive strategies. These fathers combined reality-reasoning and managing strategies to develop a view of their child as 'normal'.

In summary, normalizing strategies involved the father's efforts to mentally perceive his child as 'normal'. Fathers normalized in essentially three ways: 1) by comparing themselves to less fortunate others; 2) by focusing on characteristics of the child that did not represent the diabetes; and 3) by adjusting their perceptions and care of the diabetes so that the child's life was seen as 'normal'. Comparing oneself to unfortunate others was used by all fathers;

however, use of the other two styles of normalizing varied. Fathers who normalized by altering their perceptions tended to use the strategies of reality-reasoning and managing, while fathers who focused on normal attributes tended to use fewer cognitive strategies.

Sharing.

Sharing was the fifth strategy of emotional work. Sharing is defined as the physical, and emotional division of the diabetes care and responsibility with others, and time-limiting personal involvement. In sharing, the father reduced his burden by allocating responsibility and worry.

Sharing of the diabetes care and responsibility was accomplished by the division of labour between the mother and the father. One father's comments illustrated how sharing assisted him with his emotional work: "we learned over time that if you don't spell each other off, the stress will get to you ... its just to carry the burden a little bit easier".

Sharing was also accomplished by occasionally relinquishing control of the child's care to an alternative care-giver and "taking a break". Taking a

break may have been more difficult when the family had limited support; in this case, emotional work may have been more problematic as illustrated in the following excerpt:

> And the stress that my wife and I went through... we had our first holiday away from our children last year - it had been 6 years. ... until you leave, that kind of insidious type pressure, you don't know what it is doing to you.

Finally, the father also gradually relinquished care to the child. The child's dependence on the father was perceived as time-limited; as the child matured he/she was expected to share in the diabetes care and worry.

Sharing strategies used by the father were variable. Some fathers actively and consciously decided how they would share the burden of diabetes care; other fathers' sharing was coincidental and passive. The approach that the father used in the sharing strategy was related to the role that the father had in the care and support of the child with diabetes.

In summary, the fathers used five possible strategies in their emotional work: personalizing, reality-reasoning, managing, normalizing, and sharing.

The use of these strategies was reflected in the fathers normal approach to problems, and their involvement in the care of their child. Although each strategy was described individually, there was considerable over-lap in the strategies of reality-reasoning, managing, and normalizing. In each of these strategies, the father used cognitions in order acknowledge the reality of diabetes and deal with unrelenting worry.

Conditions for Emotional Work

The primary influencing condition in emotional work was the father's perception of support. "Support" refers to the father's perception of the degree to which he is understood, valued, and emotionally sustained. Support was derived from formal and informal sources and was perceived as adequate or inadequate. For the father of a child with diabetes, formal and informal supports provided guidance and direction, positive reinforcement, an avenue for emotional release, and respite care for his child.

Formal support systems included health professionals and support groups. The major function

of formal supports was to provide the father with information, guidance, and direction that would facilitate his acquisition of knowledge and skill. This knowledge and skill may have assisted the father with personalizing, reality-reasoning, managing, and normalizing strategies.

Health professional support was mainly educational and limited to information sharing. A father's description of his child's hypoglycaemia illustrated how health professional education assisted the father with his managing strategies, and the ultimate lessening of his worry: "And then if you get into this crisis situation - they teach you how to use glucagon. We had a bad reaction ... and it is amazing; you just - you're reactions - everything kicks in!"

Support groups were not widely used for emotional support. Only two fathers used these groups for information sharing. However, several fathers (n=4) speculated that these groups could assist them in coping with the emotional aspects of the disease. One father stated "I think that you need someone at the outset to be very practical about it and say 'you need to take some breaks and this is how you can structure

it'". Although support groups were identified as a potential source of support, most fathers (n=6) were critical of groups, and therefore, did not use them.

> Guys don't bind the way that women do ... neither the parent or the children want to sit around the room and commiserate about their problems ... it is so much easier for women to get together and share their feelings ... for guys, they need to get together and do something for those feelings to come out.

Formal support through health professionals and support groups had limited usefulness for the father's emotional work. Instead, fathers relied on informal supports while conducting much of their emotional work.

Informal supports were the primary source of support for all but one father; this father, who had difficulty with emotional work, was unable to identify a primary source of support. Informal supports were more diverse and included: the wife, the extended family, and individuals who had knowledge about diabetes. The father's perception of support from his wife was of primary importance in emotional work. Six fathers identified the wife as their major source of positive support in dealing with the emotional impact of diabetes. The wife may have performed a variety of supportive functions that promoted the father's

utilization of emotional work strategies: 1) an educator: "she became my supervisor ... and we talked about it ... and that helped"; 2) an encourager: "I'm active; that is probably more a credit to W. [wife] than me - she got me into it"; 3) an organizer: "she keeps us all together"; 4) a collaborator: "I think that it is really, really important to have a wife there so that the father can discuss problems"; and 5) an expert: "if I am not sure about things, I have W. [wife] to help me". In each of these supportive roles, the mother assisted the father with his individualized emotional work. In cases where the wife was the only source of emotional support for the father (n=2), emotional work was not impeded. These fathers reported that this support was optimal and sufficient. The second major source of support was the extended family. The extended family was a primary source of support for two fathers; however, all fathers identified the supportive role of their family. Families provided both respite care and emotional support. Fathers (n=6) who had extended families nearby, reported the benefits of that support. Two fathers made comments that illustrated the importance of the extended family: "my

side of the family is here and I can talk to anybody I want"; "they [grandparents] like doing stuff with the kids so we are really lucky; a lot a families are not that lucky". Fathers (n=4) who did not have extended families reported more difficulty with the sharing strategy of emotional work. "I guess the hardest part for us is that we don't have any immediate family in the area ... so we don't have any immediate family that can help out".

The third source of informal emotional support included other individuals who were knowledgeable about diabetes, acquaintances at work, and/or friends. With the exception of one father, these sources of support were secondary and supplemented other informal and formal support systems.

In summary, formal support provided the father with information that assisted him with the emotional work strategies; however, this support played a minor role in the father's emotional work. Informal sources of support had a major influence on the father's emotional work. Support from the wife, the extended family, and knowledgeable others all contributed to the father's emotional work. The primary, and necessary,

condition for the father's successful emotional work was the father's perception that he was sufficiently understood and supported; however, this was not always the case. If the father perceived that he was unsupported, emotional work was difficult and successful resolution may not have occurred.

In conclusion, emotional work was characterized by the father's awareness and use of energy to acknowledge the reality of diabetes and the implications of the illness. Emotional work began at the time of diagnosis; at this time the father 'worked' toward acknowledging the reality of diabetes. Dealing with unrelenting worry was continuous and resulted from concerns related to the father himself, the child with diabetes, and other family members. Fathers conducted their emotional work by using personalizing, reality-reasoning, managing, normalizing, and sharing strategies. These strategies assisted the father in coping with the emotional impact of diabetes and advanced the process of integration. The father's emotional work was most reliant on the condition of support. The father was able to conduct his emotional work when he perceived that he was the recipient of

sufficient and positive support. The components of emotional work are illustrated in Figure 2.

FIGURE 2

Emotional Work

PROPERTIES	STRATEGIES	PRIMARY CONDITION
Acknowledging the reality of diabetes	Personalizing Reality-reasoning Managing Normalizing	Perception of support
Dealing with unrelenting worry	Sharing	

The Work of Integrating: Role Work

A second, and concurrent, component of the work of integrating was role work. Role work is defined as the intentional use of energy to define, organize, and enact the functions associated with fathering a child with diabetes. At the time of the child's diagnosis, the total family was confronted with the demands of the diabetes regime. The family's roles had to be adjusted to incorporate a diabetes regime that was not temporary, but permanent. Insulin injections, blood tests, scheduled meals, routine exercise, and on-going monitoring of the child's condition had to be assimilated into daily routines if the child's diabetes was to be controlled. The father "worked" to find his own role in the support and care of his child with diabetes. The properties, strategies, and primary condition of role work are presented in the following text.

Properties of Role Work

Role work was depicted in four interrelated processes that reflected the father's efforts to define, organize, and enact his role: role extension;

role competence; role expansion; and role satisfaction. Role extension and role competence were characterized by the father's preparations for a role that included the diabetes. During role expansion, the father adopted a role that incorporated the diabetes. This role may have been: a shared-primary role; a part-time role; or a supportive role. Finally, in role satisfaction, the father found satisfaction in the role he was enacting. Each component of role work is elaborated in the following section.

Role Extension.

Role extension refers to the continuation of past fathering behaviours. The father's role with his newly diagnosed diabetic child paralleled his role functions prior to the diagnosis. New role behaviours were not developed at this time. The father was unaware of the implications of diabetes and, without this knowledge, viewed his newly diagnosed child's needs as being similar to any illness.

The family's parenting styles, and the sharing of responsibility, most influenced the father's role extension. Fathers who were involved in child care before the diabetes, viewed diabetes care as a

continuation of that previous role. Sharing in the marital relationship also influenced the father's initial role extension. For example, fathers in equalitarian families before the diagnosis, extended their role to include the same equal involvement during the child's hospitalization period. One father who extended his role to include the diabetes care in the hospital stated: "I guess we were quite equalitarian so that I don't think there was an alternative". Therefore, in role extension, new roles were not developed; the father simply extended his already established role behaviours to the care of his hospitalized child.

In summary, during role expansion new roles were not developed; previous paternal role patterns were extended to include the diabetes. The role extension of the father was related to his past style of parenting and the sharing of responsibility in the marital relationship. Fathers who were in involved and shared roles extended that involved and shared role to the care of their hospitalized child. Alternatively, fathers who had limited involvement and sharing, had a similarly limited role in the care of their

hospitalized child.

Role competence.

Although the father initially adopted a role that paralleled his previous role with his child, he had to incorporate the diabetes care into that role. His previous father role did not prepare him for the demands of the diabetes and, as a result, he attempted to develop the skills and knowledge that were necessary to care for a child with diabetes. Role competence refers to the deliberate actions that the father employed as he attempted to perceive himself as capable and confident in a role that incorporated the diabetes. Regardless of what his role was to become, the father required a self-perception of competence if he was to find, enact, and be satisfied with his role.

The father's sense of competence was derived from a sense of control over the diabetes; he felt in control when he was able to confidently care for, and respond to, the child's needs. The father's sense of control was: a) independent, that is, control was derived through personal learning, knowledge, practice and experience: "I sort of felt that I could do it and I did it ... I am more willing to just go ahead and do

it on my own"; or dependent, that is, the control was derived through the direction and supervision of others. "I don't know the meal schedule .. I never had to do it before ... so now it is written down, so now I know what to do" or "I can do it but I guess I am just lazy some days ... I sort of let W. [wife] do more ... she runs the show most of the time". Fathers who were independent in their mastery had a stronger sense of competence; they perceived themselves as capable and confident. This self-perception provided them with the basis for defining their role; these fathers adopted roles that were independent. Fathers who were more dependent in their mastery, perceived themselves as less competent; they felt less capable and less confident. These perceptions interfered with their ability to take on independent roles.

Developing role competence was the basis for the father's role work. In this phase, the father's role work reflected his efforts to learn about the diabetes and develop a sense of capability and confidence. The father's perception of his role competence supported him in the role that he eventually adopted.

Role expansion.

As the father developed competency in the diabetes care, he began to expand his role to include the diabetes. Role expansion refers to the father's intentional enlargement of his role to include all, or some, aspects of the diabetes. This process of role expansion was strongly influenced by the previous two stages, that is, the father's past experience and his sense of role competence. All fathers' roles were composed of two segments: a care-taking aspect that involved the diabetes care and responsibility; and a parenting aspect that involved 'normal' parenting functions such as discipline and support.

The fathers in the sample took on one of the following three roles: a shared-primary role; a part-time role; or a supportive role.

i) shared-primary role: The fathers (n=2) in a shared primary role had integrated diabetes care and responsibility into all aspects of their conventional father role; they had also incorporated the diabetes into other parenting functions. The father's knowledge, responsibility, decision-making, and care-taking was similar to that of his wife. Fathers who

adopted a shared-primary role had adjusted their daily routine so that they were able to equally balance the diabetes care with other aspects of their life.

ii) part-time role: In this role, like the primary role, the father was active and involved in parenting and diabetes care-taking; however, the father was not able to equally balance the diabetes care with other aspects of his life (n=3). The father's role was 'part-time'; he was unable to adjust his work routine to fully incorporate the diabetes. The father in a part-time role accepted responsibility, decision-making, and care-taking during the times when he was not at work. He was capable and knowledgeable regarding the diabetes care; he could "step in on any given time or occasion and take over".

iii) supportive role: The father who enacted a supportive role assumed a passive and limited role in diabetes care-taking. However, the diabetes was integrated into other parenting roles. These fathers (n=5) viewed their role as supportive of the wife and the child with diabetes. These fathers were capable of performing the diabetes care-taking tasks; however, a limited knowledge base restricted their decision-making

and responsibility. These fathers assumed a secondary and optional role in the diabetes care. They cared for the child when the mother was away or simply at the mother's direction. In this role, the father maintained the child's health under the mother's supervision.

In summary, role expansion was characterized by the father's efforts to include the diabetes in his role. The father adopted one of three roles: a shared-primary role, a part-time role, or a supportive role. All roles incorporated the diabetes into 'normal' parenting functions; however, the incorporation of the actual diabetes care and responsibility varied.

Role satisfaction.

The final segment of the father's role work was role satisfaction. Regardless of the father's actual role, each father attempted to find a sense of satisfaction in his role. Role satisfaction is defined as the father's expression of contentment in his role.

Most fathers (n=9) reported a sense of contentment in their role. One father who was not content, was "working" to expand his role from a supportive role to

a part-time role in order to compensate for his wife's recent employment outside of the home.

The father's sense of role satisfaction was retrospective. A sense of satisfaction was derived from a self-evaluation comparing their perception of an ideal role and their actual role behaviours. Fathers' who expressed congruence between expectations and behaviours reported satisfaction. Conversely, fathers' who expressed incongruence between self-expectations and actual behaviours expressed dissatisfaction. Thus role satisfaction was derived from an self-evaluation of actual role behaviours.

Fathers' who enacted a shared-primary role found satisfaction from their sense of control and involvement in their child's life. They felt that an active role was ideal and therefore derived satisfaction from the time that they spent with their children and the physical care that they provided.

Fathers' who were in a part-time role derived satisfaction not from the actual care that they were providing, but rather from the supportive function that their role fulfilled. These fathers felt that they could not be a "primary person" in their child's

diabetes care; however, they felt that the ideal father should share in the care and support the wife and child. These fathers derived satisfaction by reducing the wife's stress levels and caring for their child. One father described his role satisfaction in the following excerpt:

> As much as taking over responsibility for managing a diabetic child is a load, there is not much sense both parents loading up equally on it. They should try to figure out a way to divide it up, or spread it out ... because there will be times if both of you are loaded up, you will load the system too much.

Fathers who were less involved in the diabetes, and functioning in a supportive role, found satisfaction not in their role with their child or wife, but in other roles outside of the family. For these fathers, the ideal role did not include an active involvement in ill child-care, but rather involvement in instrumental functions such as financial support. One satisfied father stated: "I just channel a lot of my energy at work and around here". While a second father stated: "I have managed to make a lot more money".

Regardless of the father's actual role, finding satisfaction was important in his over-all role work.

Fathers who expressed a sense of satisfaction, appeared to reach a state of balance and stability in their role work. Once "satisfied", fathers continued to function in a variety of changing circumstances, but these functions were within the parameters of their established role. However, this satisfaction was not permanent; dissatisfaction occurred when the father's role behviours were no longer congruent with his role expectations.

In conclusion, the father's role work was characterized by four related processes: role extension, role competence, role expansion, and role satisfaction. All fathers participated in role work and found a role that incorporated aspects of the diabetes. The extent of that role varied; however, each father attempted to find satisfaction in the role that he was enacting. The process of role work was active and effortful until the father defined, enacted, and became satisfied with his role. Once this occurred a period of stability was reached; the father functioned within the boundaries of the role that he had chosen.

Strategies in Role Work

The father's role work was guided by three strategies: knowing/learning; re-defining; and restructuring. Each is discussed in the following section.

Knowing/Learning.

Knowing and learning refers to strategies that the father used to acquire an understanding and develop a sense of confidence related to the diabetes. This strategy was used in the initial phases of role work, that is, during role extension and developing role competence; it was also reflected in the cognitive work that was occurring concurrently.

The father's earliest learning strategy involved participating in some form of education. Most fathers (n=8) began their knowing/learning strategies by participating in formal education and practice sessions conducted by health professionals. This early learning provided the father with a basic understanding of diabetes; it suggested, to him, the knowledge and skill that was required to enact a diabetes role.

> And we were learning all the regime, and the scheduling, and the importance of it ... and an abundance of information as you went through the whole system... In a way, I guess

> it was to hype [sic] you up so that you think that this can be handled.

If the father was unable to participate in this early health professional directed learning, his wife became the source of this 'formal' education. In this case, the father developed a basic knowledge and appreciation for the diabetes role through his wife's tutoring. In the following excerpt, a father described his experience of learning through his wife:

> Most of the time [early education sessions] I was at work... so most of it [care] was still done by my wife. ... I would help out and try to feed her at the proper times and sort of watch the time for her and ask her what to give. That's about it.

The father's second knowing/learning strategy was finding sources of information. Participation in early learning increased the father's awareness of the complexity of a diabetes care-taking role. The father began to seek information from other people and books in order to ensure that he was able to develop the competence required to care for the diabetes.

Practice was the third approach that the father used in knowing and learning. Practice began during the hospitalization, when the parents were encouraged to participate in the diabetes care, and extended to

the early weeks following discharge. Through practice, the father rehearsed his care-taking role; this rehearsal assisted him in the 'role competence' and the 'role expansion' components of role work.

In summary, knowing and learning was a strategy that the father used early in his role work. The processes of learning about the diabetes, and extending knowledge through practice, each assisted the father in finding a role in the care of his child.

Re-defining.

Knowing and learning strategies provided the father with the basic competencies that were required for a diabetes role; in re-defining, the father determined what that role would be. The strategy of re-defining refers to the father's formation of a new role for himself that was based on his evaluation of the roles and responsibilities in his life. Re-defining was a personal strategy based exclusively on the father's perceptions of the ideal father role, and his ability to achieve that role.

In re-defining, the father attempted to assimilate diabetes into his present roles. Initially, the father appraised his notion of an ideal diabetes role. This

consideration of a role in diabetes may have been conscious or unconscious; however, the father's idealization of a diabetes role reflected earlier roles that he had found comfort in, and internalized. The father who perceived the paternal role ideal as that of breadwinner and supporter transferred that ideal to his role as a father of a child with diabetes: I'm the breadwinner ... and I try to lessen her burden a little bit - especially with my daughter". A father with a more generalized role used that same approach when defining his role with his child with diabetes:

> I'm a dad. My boy has got this condition that needs attention - he needs loving care. It is part of being a dad. Nothing is too great; nothing is too much for him.

Thus, the father's ideal role was part of his personal definition of himself. The actual definition of the father's role in the diabetes reflected his over-all perception of his role with his child.

The father's definition of an ideal diabetes role influenced the amount of effort that he invested in re-defining other roles in order to integrate the diabetes. The fathers who strived for a shared-primary role deliberately attempted to balance their diabetes

role with their work and outside interests. One father stated:

> We sort of got into the mind set that we would adjust so that I would spend time with the children ... I sort of felt that I could do it [participate in care] and I did it, and it sort of evolved ...

The part-time role required less deliberate and assertive re-definitions of roles. These fathers only priorized their roles for the time that they were away from work. The fathers in this role, accepted that their wife was in the better position to provide primary care; however, when they were at home these fathers provided diabetes care to their child.

The fathers' in a supportive role did not actively adjust their daily routine or priorize other roles. Their re-defining approach consisted of justifying the role that they were enacting. One father who enacted a supportive role stated: "W. [wife] holds more of the responsibility. You can't split responsibility. You can split duties, but you cannot split responsibility".

In summary, the father defined his diabetes role based on two separate but related perceptions: his perceptions of an ideal role; and his perceptions of his ability to incorporate the diabetes into his other

roles. The combination of these perceptions yielded the father's definition of a diabetes role given his past experience and his present circumstances.

Restructuring.

Restructuring refers to the organizational strategies that the father employed in order to fulfil his idealized role. This strategy was most apparent in the property of role expansion.

The father's restructuring strategies were both personal and social. The father re-organized each of these spheres of his life in order to incorporate the diabetes role that he had chosen. The intensity of restructuring was related to the level of involvement that the father's role entailed. The difficulty and complexity of restructuring strategies were positively related to the amount of the father's involvement in the diabetes care and parenting.

Personal components of the restructuring strategy included the father's efforts to fulfil his role while dealing with the rigidity that was inherent in the diabetes regime. The father participated in the restructuring of his daily routines, leisure activities, and communication patterns.

Incorporating the diabetes regime into the daily routine required considerable restructuring strategies, particularly for fathers who desired an involved role. The scheduling of meals, injections, and blood testing, necessitated restructuring of the father's daily routine if he was to assume a primary-shared role. "One of the big changes I suppose, is the need to be home on time.... to get home by 6:00 is a problem in my business. And this is when he needs me". Because of work responsibilities, most father's daily routine could not be sufficiently restructured to incorporate the total diabetes regime. However, fathers with flexible work situations incorporated some aspects of the diabetes care.

> I tried to be here to do the 8:00 [injection] but I found if I did that, by the time I got downtown, it was 9:30 .... I switched over to an earlier time, to a 7:30 start, so that I could be home earlier to help with supper preparations.

Fathers' who enacted part-time roles complied with personal restructuring on weekends, when work responsibilities did not interfere with the daily routine.

Personal restructuring of daily routines was optional for father's who functioned in the supportive role. Restructuring did not occur on a regular basis but rather as the situation required. "I don't mind doing it on the weekends, or the odd morning I get up. If I'm up before everyone else, I don't mind sharing things".

Personal restructuring was also required in leisure activities. The father, regardless of his role, fulfilled parenting functions that involved leisure activities. In these circumstances, the father re-organized activities to compensate for the loss of flexibility and a need to schedule activities.

> All of a sudden you have to become very scheduled and you have to really plan ahead. You can't be spontaneous ... I mean, just to take my son to a hockey game becomes a whole lot more of an effort than 'hey we got tickets to the hockey game, let's go'. Its just that you have to go to the ones at the right times and you have to work it out. Either he gets his shot in the car in the parking lot.. or we go after dinner... or whatever it is.

Communication patterns in the home were also restructured. For all fathers, the diabetes became a source of conversation and concern; communication patterns with his wife and children were re-structured

to incorporate the diabetes.

> I would come home and the first thing it would be is 'how is C.; how is her blood sugar today; was she up or down?'.
> As far as the other kids are concerned...we were really quite concerned... we have tried to be very honest and straight forward with them on it.

Socially, the father's restructuring strategies were characterized by adjusting social situations to incorporate the diabetes. Again, the amount and difficulty of this restructuring was related to the type of role the father adopted. The effort involved in social restructuring was positively related to the responsibility and decision-making functions that the father performed in his role.

Fathers in shared-primary, and part-time roles were active in their efforts to ensure that the child was cared for during times away from the parents. Social activities were restructured in several ways: one or both parents ensured that they were available in the event of an emergency; care-givers were educated to monitor and care for the diabetes; and occasions were adapted to incorporate the diabetes. For example, a simple social activity required deliberate, and careful planning. One father's statement reflected the degree

of social restructuring required: "Everything revolves around her schedule. Everything! ... When we go out, we have got to think about how long we are going out for. Do we have to take the insulin? ...".

Restructuring of social activities, and ensuring the diabetes was cared for in the parents' absence, were approaches that the father used in order to fulfil his primary-shared role, or part-time role. This strategy allowed the father to satisfy his commitment to responsibility and decision-making. Fathers' in a supportive role were not active in this social restructuring; rather the wife assumed the responsibility for organizing social situations. The father in the supportive role simply complied with the restructuring that his wife had orchestrated.

In summary, restructuring strategies were utilized as the father fulfilled his diabetes role. The extent of restructuring was related to the role that the father was attempting to enact. Fathers who were establishing shared-primary and part-time roles were active in both personal and social restructuring strategies; daily routines, leisure activities, communication patterns, social activities, and child-

care arrangements were all restructured. Fathers establishing their supportive role also participated in restructuring, but to a lesser extent. These fathers restructured leisure activities and communication patterns; daily activities were restructured on an occasional basis.

In conclusion, the father used three strategies while conducting his role work. Initially, the father supported his role development through knowing/learning strategies; these strategies provided him with the information that was necessary for him to enact a diabetes role. Secondly, the father re-defined his roles to include the diabetes; he defined an ideal role for himself that contained all, or parts, of the diabetes care. Finally, the father used restructuring strategies to adjust his personal and social world to assist him in fulfilling his role.

Conditions for Role Work

The primary condition for role work was the perceptions that the father held. Two inter-related, interactive, aspects of the father's perceptions that

influenced role work were: the father's perceptions of his wife's expectations for his role; and, the father's own view of his roles and responsibilities in the spousal relationship.

The father's perceptions of his wife's expectations exerted a major influence on the father's role work. The effort involved in finding a role, and the type of role the father adopted, were related to the father's perceptions of his wife's high or low expectations related to his involvement and capability. If the father perceived his wife's expectations as high, he was more likely to take on an involved role than the father who perceived his wife's expectations as low. One father who had a limited role, and experienced difficulty in finding a role, reported that his wife had low expectations of him:

> I think she considers me slow and idle-brained and I'm not as quick to pick up the things. She is just super organized and she just does it and its as simple as that. She says 'you do this', and I will do it. So I just do what I am told.

Fathers who perceived their wife as having high expectations reported more involved roles. One father who took on a shared-primary role stated: "I'm active! That is probably more a credit to W. [wife] than me ...

she got me into it!"

The father's perceptions of his wife's expectations interacted with the second influencing factor of role work: the father's perception of his roles and responsibilities in the spousal relationship. The father's perception of these roles and responsibilities originated with earlier experiences in the relationship that were non-diabetes related. One father's statements illustrated the interaction between past roles and responsibilities and the role work involved in finding a diabetes role.

> We have a normal on-going process that a husband and wife have anyway with just 'who is going to do what at home, and outside home' ... and we just incorporated it [the diabetes] into that on-going struggle.

Fathers' who viewed their relationship as an equal, sharing, partnership were more decisive in finding their role. These fathers took on shared-primary and part-time roles. One father stated: "She is not just my wife - she is my partner for life". A second father's also commented: "We had always wanted to run a home where we were sort of equal - and that was our attitude toward C. [child]. We both had to learn".

Fathers who perceived unequal or distinct maternal and paternal roles and responsibilities were influenced by this perception. Fathers in relationships where the wife was perceived as being in control of child-care and home-making were more likely to limit their role. Two fathers' who developed supportive roles commented on their perceptions of their roles:

> I never got up in the middle of the night ...so when we brought this kid home with diabetes, right away, my wife figured 'I am going to be doing most of this stuff'.
>
> Its just this macho thing - the ladies look after the children. And that is the role that we are raised in.

In summary, the father's role work was influenced by two interacting perceptions: the father's perceptions of his wife's expectations regarding his involvement and capability; and the father's perceptions of his own roles and responsibilities in the spousal relationship. These two perceptions interacted and influenced the effort involved in the father's role work and ultimately the role that the father adopted.

In conclusion, the process of role work was illustrated by an evolution of the father's role from a pre-established, non-diabetes role, to one that incorporated all, or parts, of the diabetes. The father's role was defined as: a shared-primary role; a part-time role; or a supportive role. Fathers conducted their role work by using three strategies: knowing and learning, re-defining, and restructuring. The type of role that the father adopted, and the difficulty he had in finding this role, was primarily influenced by the father's perceptions of his own, and his partners, role expectations. A model depicting role work is illustrated in Figure 3.

FIGURE 3

Role Work

PROPERTIES	STRATEGIES	PRIMARY CONDITION
Role extension Role competence Role expansion Role satisfaction	Knowing/learning Redefining Restructuring	Perception of own and wife's role expectations

The Work of Integrating: Cognitive Work

The third component of the work of integrating was cognitive work. Cognitive work refers to the use of energy in an effort to develop a diabetes knowledge base and diabetes care-taking skills. The parents of a child with diabetes were faced with acquiring an imposing amount of information about diabetes and diabetes care. At the time of the diagnosis, little was known or understood about the disease. Injections, blood testing, urine testing, accounting for food and exercise, and dealing with acute medical emergencies, were foreign to 'normal' parental functions. However, in a matter of days, the parents were expected to include these diabetes care tasks into their parenting behaviours. This inclusion, and the ultimate integration of diabetes care and parenting, required an immense amount of theoretical and practical learning. The properties, strategies, and primary condition of cognitive work are presented in the following section.

Properties of Cognitive Work

Cognitive work was characterized by the father's increasing knowledge and skill development. The father's capabilities ranged from: an apprentice who was unskilled, ignorant, and dependent; an assistant who depended on others for guidance but had a basic level of skill and knowledge; and finally, a specialist who was expert, skilful, independent and capable.

Apprentice.

The father began his cognitive work as an "apprentice", that is, he was unknowing, unskilled and required direct tutoring and supervision. This stage began at diagnosis and continued until the father was able to perform basic diabetes care-taking tasks. These basic tasks included: insulin injections, blood and urine testing, following a meal plan, and recognizing and treating a low blood sugar.

As the father entered his diabetes apprenticeship, he had little knowledge about the diabetes and was not cognizant of the implications of his child's diagnosis. Most apprentice fathers relied on health professionals to direct their learning. Two fathers' comments illustrated this reliance:

> I had to attend command performances to be taught about what diabetes is and all those other kinds of things ..."
>
> She would say they are having a course today on nutrition; you are expected to go up there and listen. So they told me where I should be, and I'd go.

Fathers who were not available for health professional directed learning, depended on their wife to educate them. One father who had been educated by his wife, related his coincidental and unstructured learning during his apprentice stage:

> I started watching my wife more often - what time breakfast was, what time lunch was. I started asking more questions as to what food she's eating, what is good for her at lunch time, and what not.

The father was also dependent on health professionals, or another diabetes expert, while he was acquiring diabetes skills. He was personally supervised and directed as he practised the diabetes care tasks.

While an apprentice, the father had little knowledge about the child's unique reactions; the child's response to food, exercise, and abnormal blood sugar levels were not known. This lack of knowledge was articulated by a father whose child experienced a severe reaction as a result of a lack of knowledge

about the child's response to exercise: "... we had a bad reaction, a severe reaction because we didn't feed her enough ... we have learned now".

Because of a lack of diabetes knowledge, and uncertainty about the child's responses, the diabetes regime was rigidly adhered to. Compliance to the diabetes regime was absolute. Foods were weighed and measured, schedules were strictly adhered to, and blood testing was frequent.

In summary, the father, as an apprentice, had a beginning level of knowledge. His approach to the diabetes was simplistic, regimented, and insecure. The father depended on others to coordinate his cognitive work; he required supervision and direction. This supervision and direction originated with health professional directed education, or the wife.

Assistant.

The father as an "assistant" had achieved a basic level of knowledge and skill; however, he required assistance in decision-making and problem-solving. The assistant was capable of caring for the child but lacked the knowledge and experience that was required for the provision of independent care. During this

stage, the father was not capable of complete responsibility, decision-making, and problem solving; he relied on others to assist him in his practical learning of diabetes care-taking. The assistant stage began when the father had acquired a basic level of skill and knowledge; this usually occured following the completion of a hospital education program. The stage ended when the father was capable of independent care, responsibility, and decision-making.

The assistant father conducted his cognitive work by attempting to expand his theoretical and practical knowledge base. During this stage of cognitive work, the father's theoretical knowledge was guided by his own independent efforts to gain information. He sought out information from other individuals, read literature, and participated in the diabetes care. The father's theoretical knowledge development was enhanced by care-taking experiences. Experiences grounded the father's knowledge in reality; theoretical knowledge took on practical significance. "You can read all the books you want, and people can tell you all about it, but until it happens...".

Practical knowledge was attained through, or with,

the wife; the father gained practical knowledge as he 'assisted' his wife in the diabetes care-taking. This assistant stage of practical knowledge acquisition was characterized in three ways: 1) equal and shared assistantship with the wife. "and so we both were reading the book, and figuring it out, and telling each other what was happening"; 2) fluctuating, shared assistantship. "I wasn't as comfortable with his disease as my wife was ...her skill level progressed very well and she became my supervisor on it ... now my wife is as expert as I am"; and 3) unequal shared assistantship. "she had more of the say and more of the training ... I will always ask her ... she is like the expert".

The three variations in the father's assistantship related to the role work that was occurring concurrently. Fathers who were attempting to develop an active role participated in an equal shared assistantship, or a fluctuating assistantship, with their wife. These couples worked together to develop problem-solving skill and independence. At times, the father's and mother's knowledge and skill level was unequal due to work-imposed lapses in the father's

care-taking. However, this inequity was temporary; the mother tutored the father until his knowledge and skill level was equal to hers.

Fathers who were attempting to adopt a supportive role may have experienced a shared equal assistantship initially, but because of limited involvement in the child's care, the mother soon developed more skill. In this case, the mother was perceived as being more skilled and knowledgeable; she became the father's supervisor. Without active efforts to advance the father's knowledge and skill, this inequity between the father and mother remained. The father's cognitive work remained in the assistant stage; he had basic knowledge and skill but lacked the experiences that were required for problem solving and responsibility.

In summary, at the beginning of the assistant stage, the father had a basic level of knowledge and skill. The goal of the father's cognitive work at this time, was to advance theoretical and practical knowledge to a level where problem-solving and responsibility could occur. This advancement occurred through the father's independent acquisition of theoretical knowledge, and through assisted practical

learning. Assisted practical learning occurred with the wife; it was shared and equal, shared and fluctuating, or shared and unequal. All fathers experienced the assistantship stage; however, fathers who took on an active diabetes role advanced to the next stage while fathers taking on a less active role did not.

Specialist.

The final stage of cognitive work was characterized by the father as a "specialist". Self-learning, and shared experiences, provided the father with numerous learning opportunities. This learning advanced the father's theoretical and practical knowledge to a stage where he perceived himself as a specialist in his child's diabetes care. The fathers who progressed to this level in their cognitive work were knowledgeable, skilful, confident, independent, and flexible. Two fathers' comments illustrated the confidence and knowledge typical of this stage:

> When you are dealing with it constantly, you are the specialist. You have to be.
>
> I started to realize at that point that nothing was happening and no one was helping us but ourselves ... There is no question, parents know a lot more [than doctors].

The diabetes care tasks were less arduous for the specialist father. His level of knowledge, and abundant experiences with the diabetes, provided him with skill and comfort in carrying out the diabetes regime. "Today, I can cut a banana within 2 grams of its weight .. . you know, its amazing". Nuances of the diet were assimilated, and the responses of the child could be predicted. Through this knowledge, the diabetes care became more individualized and less uncertain.

> We fine tune ... a 1/4 of a tablespoon of peanut butter for his snack at night; you know, it is just how he is. You sort of react a little bit to how he is behaving without even doing a blood test.

In the specialist stage, the father had a high level of understanding about his child's unique responses. Through increasing knowledge, experience, and problem-solving, the father was able to ascertain how the child would respond to various stimuli. One father's description of his child's low blood sugar demonstrated this integration of knowledge and experience: "So he had gone low through a combination of a warm day, soccer game at lunch, and the fact that he was cheating on his diet".

In this stage, the father's cognitive work advanced to a critical level. He independently gathered information from a variety of sources and integrated that information to develop an individualized approach for the care of his child. A father's discussion of his use of literature, his wife's knowledge, and his own experience exemplified the critical thinking that was characterized in this stage: " ... and we comment on it, we talk about it, and we try to figure out our own strategy on how to work things". This critical and individualized approach provided the father with the competencies that promoted independent goal setting.

> We have formed our own opinion ... we were adamant that we were going to keep the sugars within a range even if that meant walking him at night, or cutting his food, or feeding him every hour.

The father as a specialist was knowledgeable, skilful, independent, and confident. Typically the father who had attained this level of cognitive work had been involved in a shared-primary or part-time role, and had participated in on-going self-education. The father's experience, and knowledge, each contributed to his sense of expertise which, in turn,

allowed him to provide independent, individualized, and skilful, care to his child.

In summary, the father's cognitive work progressed through three stages: apprentice, assistant, and specialist. The progression through these stages was characterized by advancing knowledge, skill, independence, confidence, and flexibility. The father accomplished these stages first through direct tutoring and supervision, then shared experience and problem-solving, and finally independent learning, experience and decision-making. Each father's cognitive work did not progress through all three stages. Some fathers, who had chosen less active roles with their child with diabetes, remained in the assistant stage.

Strategies in Cognitive Work

The father conducted his cognitive work by utilizing three interdependent and related strategies: searching; acquiring; and experiencing. For clarity, each of these strategies are presented individually; however, they were inter-related and used collectively during the father's cognitive work.

Searching.

The father conducted his cognitive work by searching for sources of information. The father "searched" by seeking out sources of information that assisted him in gaining theoretical and practical knowledge. Searching strategies were active or passive, flexible or inflexible, and simple or complex.

The style of searching that the father used varied throughout the stages of cognitive work. When the child was diagnosed with diabetes, the father was confronted with his lack of knowledge. He required basic information about the diabetes yet the hospitalization of his child left him with little time and energy to seek out information. At this time, the father's searching strategies were passive and simple. He did not know what he needed to know, or where to go for information; he wanted the basic information that was required for the care for of his child.

> The information you first get ... is pretty simplistic stuff - but that is just about where you are ... in the initial stages you can only cope with so much coming in.

During this early cognitive work, the father was willing to accept information from health

professionals, watch the videos they provided, and read the literature that they suggested. The father relied on these formal sources of information because they were accessible, structured, and available. The father did not demonstrate flexibility in his searching at this stage. He simply accepted what he was given and did not look for alternative sources of information.

If these structured and assessable formal sources of information were not included in the father's searching strategies, early learning was prolonged. The father had to search for another source of information that was accessible, structured, and available. This alternative source was the wife; however, the father could not proceed with his learning until his wife had gained sufficient information to instruct him. This delay in finding a source of information extended the father's searching strategies.

Following the apprentice stage, the father's searching strategies became more active and flexible. The father's experiences with his child led him to the realization that he had only basic information. Several fathers' statements revealed this realization:

> There didn't seem to be much individualization in terms of trying to establish what we do and what we were.
>
> We would have liked a lot more information. We got the real basic stuff; we wanted more.

At this time, earlier formal sources (health professionals and literature) continued to be utilized; however, they were expanded to meet the family's individualized needs. All fathers expanded their use of the literature as they attempted to find sources that addressed some of their unique concerns. As one father stated: "I am more interested in the more scientific level .. so we have got a fair bit of literature on the disease".

The father also became more flexible in his searching; he began to seek out informal sources of information. He searched for other individuals who either had diabetes, or who were knowledgeable about diabetes. "A gentleman at work has diabetes ... I will ask him questions ... its good practical advice". Some fathers' searching efforts revealed that their wife was an excellent informal source of information.

Finally, in the specialist stage, the father's searching efforts were active, flexible, and critical. The father searched for multiple sources of information

and compared and contrasted this information in order to establish his own goals and beliefs. Formal and informal sources were utilized and critiqued. The father no longer passively received information, but rather critically examined it for its usefulness in his own unique situation.

There was individual variation in the searching strategies of the father. The extent of searching was related to the role that the father was assuming in the care of his child. Although not related to the education, or occupation of the father, fathers who were in an involved role were more active and flexible in their searching strategies. Fathers who were in less active roles tended to search for sources of information that were readily accessible; specifically, their wife or other individuals who they had frequent contact with.

In summary, searching strategies varied with the stage of cognitive work and the concurrent role work. Fathers' searching strategies evolved from passive, simple, and inflexible to active, complex, and flexible. Fathers adopting involved roles were more variable in their searching strategies.

Acquiring.

Initially, the father's cognitive work was guided by searching for information. Once sources of information were found, the father's attempted to acquire, or "take in" that information. In acquiring, the father attempted to comprehend diabetes information; he had to attend to, and understood the information.

Initially, the father attended to the information, that is, he made himself available to receive his sources of information. At the same time, the father attempted to understand the information that he was confronting. The father's acquiring strategies consisted of some, or all, of the following: participation in formal education sessions or support groups; consulting with health professionals; reviewing written literature; use of the media; and discussing the diabetes with knowledgeable lay people. In each of these circumstances, the father used these sources to understand the diabetes and the diabetes care.

The father's approach to attending to, and understanding information either advanced or hindered his cognitive work. Fathers who interacted with

multiple sources of information moved through the stages of cognitive work more quickly than those fathers who were less interactive with fewer sources of information. For example, fathers who combined at least three sources of information (literature, health professionals, and wife) were more successful in their acquiring strategies; these fathers were more knowledgeable and demonstrated advanced cognitive work. Alternatively, fathers who used less than three sources of information had more difficulty acquiring information and had difficulty advancing to the specialist stage of cognitive work.

In summary, acquiring strategies consisted of attending to sources of information and understanding those sources of information. The father's acquiring efforts were promoted by the interactive utilization of multiple sources of information.

Experiencing.

The final strategy of cognitive work was that of experiencing. Experiencing refers to the active participation in incidents that occured as a result of the child's diabetes. The father practised, and acted, based upon his understanding of the diabetes. The

earlier strategy of acquiring, and the strategy of experiencing often occurred concurrently. Acquiring was often only realized when the father had an opportunity to "practice" his knowledge. One father's comments illustrated the relationship between acquiring and experiencing:

> You can read the literature and all that stuff; that will give you sort of a brush with it but you don't really get the same flavour as you do when you are right there doing it. That's when you get the hands-on experience.

Each new experience brought with it the challenge of a new problem which had to be solved. This on-going problem solving further advanced the fathers cognitive work.

The father's participative efforts fostered his knowledge and skill; he was provided with the practical experience that was required to advance his knowledge. These same experiences provided the father with information that was unique to his child and promoted his problem-solving. For example, one father related how he learned about his child's response through practice: "sometimes you inject him certain ways and it hurts more ... and I sort of learned that way".

In summary, experiencing strategies involved the

father's active participation in the variety of incidents that occurred as a result of his child's diabetes. Active participation in diabetes care-taking tasks provided the father with practical knowledge and skill as well as the opportunity to participate in problem-solving. This participative learning advanced the father's cognitive work both theoretically and practically.

Conditions for Cognitive Work

The primary condition for the father's cognitive work was the father's perception of his capability. Capability was an internal process that is defined as the father's perception of his own confidence and ability. The stage of the father's cognitive work, and the strategies that he used, were influenced by his father's capability for acquiring information and skill. Fathers' who perceived themselves as capable, or confident and able, advanced through the stages of cognitive work more quickly. Fathers' who perceived themselves as less capable progressed more slowly and used fewer strategies; these fathers had difficulty advancing to the specialist stage of cognitive work.

The father's sense of capability influenced how he conducted his cognitive work and ultimately the role work that occurred concurrently. All fathers were aware that if they were to adopt an active role, they would require the knowledge and skill that was inherent in that role. "You have to know it, so you have got to learn it!". Fathers striving for active roles reported that their cognitive work was rapid and integrative: "within three months you will have adapted". These capable fathers achieved the specialist stage of cognitive work within a year of the diagnosis. Fathers in less active roles had prolonged cognitive work. These fathers (n=5) have remained in the assistant stage of cognitive work for five to seven years.

The father's capability also influenced the strategies that were utilized during role work. Fathers who perceived themselves as confident and able, utilized many sources of formal and informal information. These fathers searched for, and received, information from health professionals, the media, literature, and other individuals; they gained practical knowledge from active involvement in their

child's care. Conversely, less confident and able fathers exhibited a strong reliance on their wife as a source of information. Other sources tended to be simplistic and focused; there was limited contact with health professionals and a basic level of literature was used.

In summary, the father's capability, or confidence and ability, to acquire knowledge and skill influenced the stage, and strategies, of his cognitive work. Fathers who were capable and seeking an active role advanced to the specialist stage of cognitive work, while those fathers who were less capable and not seeking an active role remained in the assistant stage. Secondly, the father's capability influenced the strategies that the father used during his cognitive work. Capable fathers relied on several sources of information, while less capable fathers were more narrow in their use of information.

In conclusion, cognitive work was characterized by the development of the father's diabetes knowledge and skill. The father's cognitive work progressed through three stages: an apprentice stage, an assistant stage, and finally, a specialist stage. In this study, all

fathers reached the assistant stage at some point during their cognitive work; however, only five fathers had reached the specialist stage. Fathers' conducted their cognitive work by relying on three related strategies: searching for sources of information; acquiring knowledge; and experiencing the diabetes and the diabetes care-taking. The fathers' use of these strategies varied depending on the stage of their cognitive work and the degree of their involvement with child care. The primary condition for the father's cognitive work was the father's capability, or his perception of his own confidence and ability. Figure 4 illustrates the components of cognitive work.

FIGURE 4

Cognitive Work

PROPERTIES	STRATEGIES	PRIMARY CONDITION
Apprentice Assistant Specialist	Searching Acquiring Experiencing	Perception of capability

Conclusion

The father of a child with IDDM "worked" to integrate his child's diabetes into his life. Energy was used to accomplish the tasks of each type of integrating work. This energy was characterized by the active and intense use of physical, emotional, and intellectual effort to achieve an objective or produce a change. Emotional work involved the awareness and use of energy to acknowledge the diabetes and the implications of the illness. The father worked to acknowledge the reality of the diabetes and deal with unrelenting worry. The second type of integrating work was role work. Role work refered to the intentional use of energy to define, organize, and enact the functions associated with fathering a child with diabetes. Finally, the third type of work, cognitive work, refered to the use of energy in an effort to develop a diabetes knowledge base and diabetes care-taking skills.

CHAPTER FIVE

THE BEGINNING SUBSTANTIVE THEORY

INTEGRATING DIABETES INTO EVERYDAY LIFE: THE EXPERIENCES OF FATHERS

Introduction

In this chapter, an elaboration of the theory of integrating is presented. This theory reflects a conceptualization of fathers' responses to their pre-adolescent child's diabetes. This chapter is presented in two sections. The first section provides a description of the theory of integrating and is presented in three parts: first, an overview of the theory of integrating is presented; second, a synthesis of the phases, and the work of integrating is outlined; and third, the phases and work of integrating are illustrated with two case examples. In the second section, the theory of integrating is outlined and a model depicting the theory is proposed.

Integrating: Discovering, Reordering, and Internalizing

Integrating: An Over-view

The analysis and resulting conceptualization of the qualitative data led to the development of a beginning process theory titled: Integrating Diabetes into Everyday Life: The Experiences of Fathers. "Integrating diabetes" refers to the father's assimilation of his child's diabetes into all spheres of his life; diabetes is included in the father's view of himself as a father, and his everyday world. This process of integrating is represented in three inter-dependent phases: discovering the meaning of the diabetes; reordering patterns of daily living; and internalizing change. The impetus for the movement through these phases is the father's evolving perception of his diabetic child's needs. Resolution of these phases of integrating occurs as a result of the father's use of energy to accomplish emotional work, role work, and cognitive work. Integrating is realized when the father, through his "work", resolves the phases of discovering, reordering, and internalizing. Movement through these three phases is

not a distinct, linear, unrelated process but rather a fluid, ongoing process that is the reflection of interdependent, overlapping experiences.

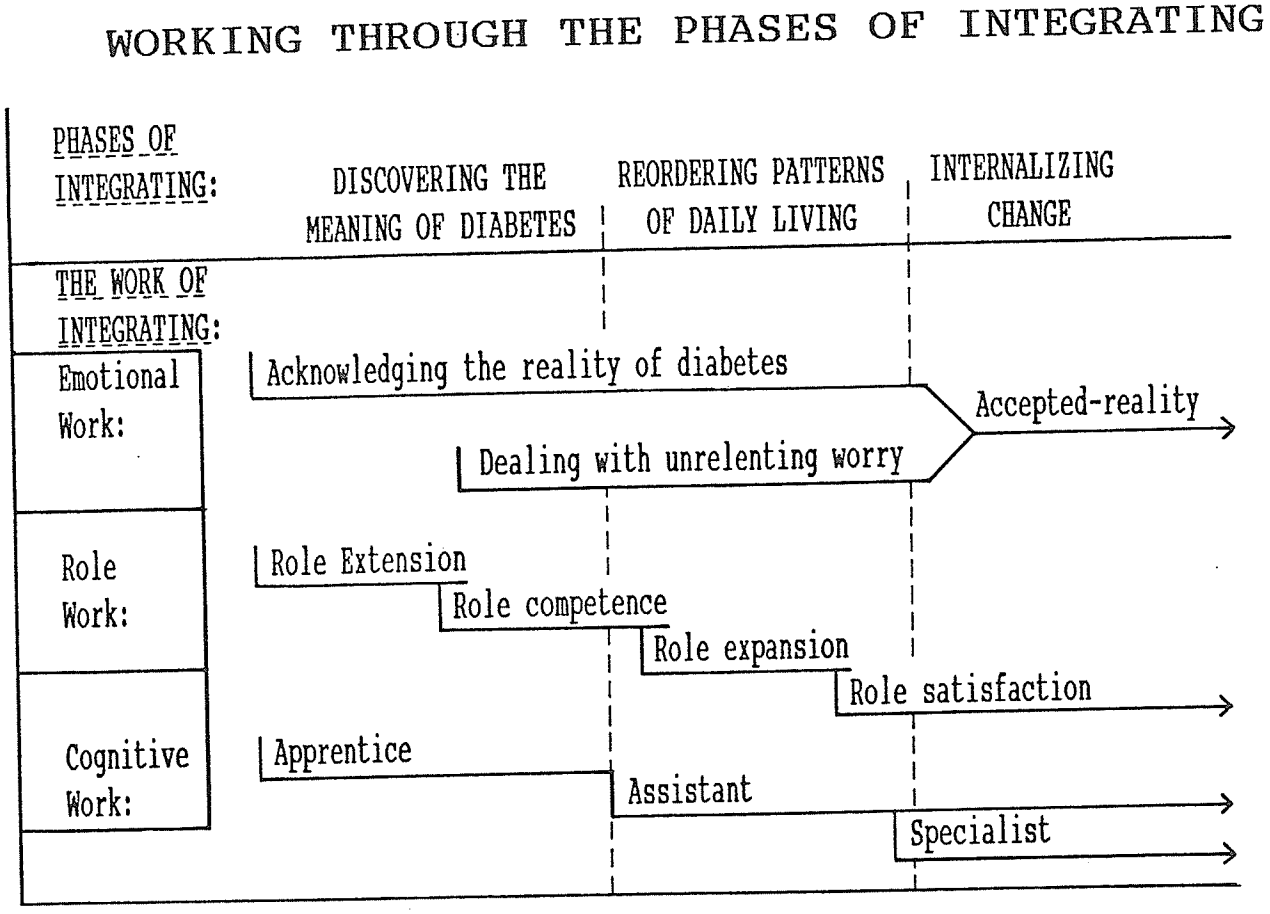
Without exception, all fathers experienced the phases of discovering the meaning of diabetes and reordering patterns of daily living. Seven of the ten fathers had also achieved the phase of internalizing. However, three fathers remained in the reordering phase. One father, who had previously internalized, was conducting role work and cognitive work characteristic of the reordering phase; this resurgence of reordering work was a result of changes in the family when his wife returned to work. The remaining two fathers were functioning in the stage of reordering; these fathers continued to struggle with the emotional work of acknowledging the reality of diabetes and dealing with unrelenting worry.

Working Through The Phases of Integrating

Integrating is accomplished when the father's emotional work, role work, and cognitive work is successful in resolving the phases of discovering, reordering, and internalizing. A synthesis of the

phases of integrating and the work of integrating is presented in the following text. This section is introduced with a model (see Figure 5) depicting the relationship between the phases, and the work of integrating. Following this model, an elaboration of the three phases of integrating, and the work characteristic of each phase, is presented. The text is concluded with two case examples that are used to illustrate the process of integration.

FIGURE 5


WORKING THROUGH THE PHASES OF INTEGRATING
PHASES OF INTEGRATING:
DISCOVERING THE MEANING OF DIABETES
REORDERING PATTERNS OF DAILY LIVING
INTERNALIZING CHANGE
THE WORK OF INTEGRATING:
Emotional Work:
Acknowledging the reality of diabetes
Accepted-reality
Dealing with unrelenting worry
Role Work:
Role Extension
Role competence
Role expansion
Role satisfaction
Cognitive Work:
Apprentice
Assistant
Specialist

Discovering the Meaning of Diabetes: Uncovering Pieces of the Mystery

The initial phase of integrating is discovering the meaning of diabetes. This 'discovering' introduces the father to the reality of diabetes; the implications of diabetes are slowly uncovered. In this phase, the father makes four discoveries: 1) his child has diabetes; 2) diabetes is a complex and multifaceted condition; 3) the care-taking demands are numerous, complex, and unrelenting; and 4) potentially, the diabetes can influence all aspects of his life. This phase of discovering begins at the time of the child's diagnosis.

The father begins his emotional work, cognitive work, and role work in an effort to cope with the "discoveries" of this phase. Emotional work is significant. All fathers struggle personally as they attempt to cope with the diagnosis and the related care-taking demands. Fathers also conduct emotional work as they deal with the impact that the diabetes has on their wife and their well children. The father's emotional work is dominated by the work typified in the property 'acknowledging the reality of diabetes'; the

work of 'dealing with unrelenting worry' is commenced, but less significant.

Cognitive work is also significant during the discovering phase. The father attempts to understand the pathophysiology, complications, and care-taking demands of diabetes. Cognitive work is demanding as the father struggles to assimilate information that is foreign, yet necessary for his child's care. In this discovery phase, cognitive work is exemplified in the property titled 'apprentice'.

Finally, role work also begins at a preliminary level. The father is expected to begin basic role work immediately following his child's diagnosis. He is asked to adjust his other roles and responsibilities so that he may participate in formal education sessions. During this phase of discovery, the father also begins to consider what his role and responsibilities might be. Role work at this time is characterized by two properties: role extension, and to a lesser extent, role competence.

Emotional work, role work, and cognitive work allow the father to progress through this phase of discovery. The work of this phase is complete when the

father has developed an understanding of the diabetes and the diabetes care demands. The "understanding" that marks the termination of this phase is demonstrated by: 1) the father's ability to carry out the diabetes care-taking tasks (insulin administration, blood testing, urine testing, following a written meal plan, treating hypoglycaemic reactions, managing exercise); 2) the father's knowledge of the diabetes schedule; 3) the father's knowledge of the cause, basic pathophysiology, and management of diabetes; and 4) an awareness of his child's early emotional response to his diabetes.

Although the discovering phase begins at diagnosis, it may be re-entered at any time. The work characteristic of this phase may be required when the father encounters changes in his child's diabetic condition that require additional "discovery of meanings". Examples of such changes may include: medical emergencies such as a hypoglycemic seizure or diabetic ketoacidosis; the development of complications; or the diagnosis of another illness.

To summarize, in this phase, the father develops a realization and understanding of the diabetes and its

implications through his emotional, cognitive, and role work. Emotional work and cognitive work are dominant during this phase; the father must cope and learn in order to discover. Initially, fathers enter this phase at diagnosis; it is completed when the father perceives himself as having a basic understanding of the disease and an ability to carry out basic care-taking fuctions.

Reordering Patterns of Living: Developing an Ordered Existence

The second phase of integrating is reordering patterns of daily living. This phase follows the phase of discovering; however, the two phases may over-lap. At this time, the father understands the implications, and the demands of diabetes; however, he has not yet structured his life to include the diabetes. The reordering phase is characterized by the father's efforts to expand his daily routine to include the diabetes. Patterns of living are reorganized in order to ensure that the child's care-taking and monitoring needs are met. Reordering of patterns includes: 1) incorporating the diabetes care into the daily routine, that is, six meals, one to two insulin

injections, four to six blood tests, routine exercise, urine testing, continuous monitoring, and treatment of acute complications; 2) ensuring on-going monitoring and supervision of the child; 3) establishing family members roles and responsibilities; 4) adjusting leisure, and social activities, and 5) finding satisfaction in reordered activities.

The phase of reordering patterns may be lengthy. At the beginning of this phase, the father's attempts to reorder require effort. The beginning of this stage is marked by: 1) a sense of worry and stress associated with establishing family routines; 2) a sense of worry and stress when diabetes routines are not strictly adhered to; 3) conscious, deliberate thought surrounding the diabetes care-tasks and problem-solving situations; 4) few family members and friends knowledgeable regarding the diabetes; 5) reliance on health professionals and knowledgeable others for direction regarding the diabetes; and 6) a personal sense of stress and anxiety regarding the diabetes and its implications.

Successful resolution of the challenges of the reordering phase are dependent on the father's work.

During this phase, emotional work, cognitive work, and role work are occurring concurrently; however, role work is dominant. In role work, the father is struggling to find his role in the care of the child; he works to find a role and then reorganizes his patterns of living based on that role. The properties of the fathers' role work at this time include: the continuation of "role competence", and the emergence of "role expansion".

The father's emotional work persists during this phase. The father continues to acknowledge the reality of diabetes; he is also confronted with the emotional work of "dealing with unrelenting worry". This additional emotional work is associated with the father's role work. As the father expands his role to include the diabetes, he is faced with worry regarding his responsibility, the child's health, and his family. Even if the father does not expand his role, he is confronted with worry about his wife and family.

Cognitive work parallels role work during the reordering phase. The father works to advance his theoretical and practical knowledge in order to support his role with the diabetes. The intensity of cognitive

work is congruent with the intensity of role work. Fathers who have a major role expansion, will conduct significant cognitive work in order to develop the competencies necessary for their role. The property of role work, that is typical during this phase of reordering, is the "assistant" although some fathers begin cognitive work characteristic of the "specialist" during the later stages of this phase.

As the father works and progresses through the reordering stage, patterns of living evolve and the intensity of the father's stress lessens; diabetes routines become less formidable and more customary. The end of this phase is marked by the attainment of a sense of stability. Change in patterns are no longer required; the diabetes care and the diabetes itself become routine. Indicators of the termination of this phase are: 1) a lessening of worry, thinking, and problem-solving as the diabetes and care-taking have become "routine"; 2) family members are aware of, and fulfil functions related to the diabetes spontaneously; 3) family and friends are knowledgeable regarding diabetes; 4) a lessening reliance on health care providers and knowledgeable others for direction; 5)

the father articulates his personalization of the accepted-reality of his child's diabetes; and 6) the father expresses contentment with his patterns of daily living.

Resolution of this phase is not necessarily permanent. Although stability may be reached at one point in time, reordering of patterns may be necessary at some time in the father's future. Like all phases, this phase may be re-entered at times when the father's perception of his child's needs changes. Changes in the child, the family, or the diabetes regime may alter the father's perceptions of his child and require adjustments to the established patterns. For example, one father returned to this phase following his wife's return to part-time work. His established patterns of living were no longer functional. All three types of work were resumed as he assumed more responsibility for the diabetes management and decision-making.

To summarize, in the phase of reordering, the father works to develop an ordered existence that includes the diabetes. The father achieves this through role work, cognitive work, and emotional work. However, this work is dominated by role work; emotional

work and cognitive work support the role work. This phase begins when the father has achieved a basic understanding of the diabetes and terminates when the father has established, and adapted to, a personal pattern of living that incorporates the diabetes.

Internalizing Change: When Change is no Longer Viewed as Change

The final phase of integrating is described as internalizing change. This stage follows the reordering phase; the father has established stable patterns of living and is satisfied with those patterns. Movement into this phase is subtle and is only realized retrospectively. The phase of internalizing change reflects a point in the father's life where the changes that have occurred as a result of the diabetes, are no longer conscious. The father has internalized the experiences that have led to change, and has assimilated them into his internalized view of himself as a father and his everyday life. Fathers who are experiencing the phase of internalizing retrospectively identified several indicators that will be described and illustrated with excerpts from the

data: 1) a reality-reasoning acceptance of the diabetes: "you become reconciled to what the diabetes means; and "there is no point moping about it - as long as we do the best that we can ... I think that I have adapted"; 2) a lack of consciousness regarding the demands of the diabetes: "you are no longer conscious and the intensity is far less - it is less draining and stressful"; 3) a retrospective sense of contentment: "realizing that there was really nothing that I could have done different" and "you have to sort of say 'well I have done the best that I can do'; and 4) a new sense of normalcy that includes the diabetes: "its [the diabetes] been around for so long that we continue on; you don't even think about it - you just do it".

In this phase, emotional work, cognitive work, and role work are no longer separate and distinct. In emotional work, the father has reached an accepted-reality; worry about the diabetes is minimized through control. Cognitively, the father is defined as either an assistant or a specialist; this level of cognitive work is relatively stable. Role work is characterized by a sense of role satisfaction. The father accepts his role for what it is and no longer strives to find

an alternate role.

In spite of an apparent equilibrium, integrating work continues during the internalizing phase. The demands of diabetes are unremitting; disregarding them threatens the child's health. Thus, in the phase of internalizing, the work of managing diabetes continues; however, the intensity, awareness of change, and emotional responses, lessen. Life with diabetes becomes part of everyday life.

Although the phase of internalizing can be relatively constant, there is always the possibility for change. Structural or functional changes in the family, and/or a change in the child's condition or the diabetes regime, may challenge the father's perception of stability and normalcy. As a result, the father may conduct "work" that was characteristic of earlier phases; discovering or reordering may be necessary. Several fathers cited experiences that illustrate how changing perceptions motivate the return to the work that is characteristic of earlier phases. Witnessing their child's hypoglycemic seizure hurled two "internalized" fathers back to the discovering and reordering phases. These fathers' perception of

stability was thwarted when, for the first time, they realized that their child's life was threatened. These fathers had to "discover" the meaning of their child's seizure and deal with renewed worries. Once they understood the implications of the seizure, they reordered their patterns of monitoring and care-taking in order to minimize the threat of further seizures. In both cases, the fathers successfully conducted their work and returned to the internalizing phase. However, their accepted-reality had changed; life-threatening seizures were now part of their reality.

Internalized fathers also experienced altered perceptions of their child's needs during: the child's school entry; changes in the mother's or father's occupational status; the birth of another child; and the child's changing responses to the diabetes. In each of these cases the fathers returned to the work that is characteristic of the discovering or reordering phases. Most often the fathers resolved this work and returned to the internalizing phase. However, one father continued to "work" in an earlier phase.

In summary, in the phase of internalizing change, the changes that have occurred as a result of the

diabetes, are no longer conscious. The father has internalized the experiences that have led to change, and has assimilated them into his view of himself as a father, and his everyday life. However, this phase may not be permanent. Changing perceptions of the child's needs may require a renewal of the work characteristic in the discovering or reordering phases. The father may remain fixed in these earlier phases of integrating, or he may return to the internalizing phase.

In conclusion, the process of integrating is realized through three related, and interdependent phases: discovering the meaning of diabetes; reordering patterns of living; and internalizing change. The indicators of these phases are presented in Appendix I. Advancement through these phases is realized through the father's emotional work, role work, and cognitive work. The father's movement through these phases is not linear but rather fluid. He may conduct the work for the phases concurrently or separately; he may also move back and forth between phases as his perceptions of his child's needs change.

Exemplars of The Father's Experiences in Working Through The Phases of Integrating

The informants provided rich descriptions of their experiences with their child's diabetes. Seven of the informants had reached a state of internalizing. The remaining three subjects remained in the phase of reordering. The phase that the father occupied related to his success in conducting the work of integrating. Two case examples will be presented to illustrate the process of integrating. In each case the duration of the child's illness was five years. In the first case, called Father A., a father who had achieved integration is illustrated; the second case, Father B., depicts a father who was suspended in the phase of reordering.

Father A.: Achieving Integration

The following discussion reflects the experiences and the words of a father who had achieved integration. This father related his successful use of emotional, cognitive, and role work through each of the three phases of integrating.

Discovering the meaning of diabetes.

This father's description of his thoughts and emotions during his child's diagnosis and hospitalization are typical of the discovering phase. Discovering the meaning of the diabetes had an emotional impact; the father discussed several responses that indicated the property of acknowledging the reality of diabetes. Reactions to the diagnosis included crying, a distraught feeling, and a desire to relieve his child of pain. The father reported other emotions that indicate the property of acknowledging; growing realization and taking on responsibility were both expressed: "all of a sudden you have to become very scheduled, and you have to really plan ahead... that really upset us ... this was our responsibility; no one else was going to do it". The father also described a lack of knowledge that is typical of the discovering phase: "we didn't know anything about the disease... and we didn't understand the implications".

The father immediately employed emotional work, cognitive work, and role work strategies to cope with the challenges of this discovering phase. For this father, cognitive work and emotional work were more

frequent than role work; however, all three types of work did occur. Emotionally, he used managing and sharing strategies. Cognitively, he sought out health professional education, attended education sessions, and participated in his child's care. Role work included adjusting his work to enable him to participate in diabetes education. He also began re-defining strategies; he defined his past role in child care as active and shared, and wanted that role to continue.

The employment of these emotional, cognitive, and role work strategies aided the father's rapid progression through the discovering phase. Following an intensive one to two week period of 'work', this father completed the discovering phase and entered the next phase of reordering.

Reordering patterns of daily living.

The father began this phase of integrating following his child's discharge from hospital. Again, he had many experiences that were typical of this phase. He continued to adapt to the notion that his child had a chronic illness; however, dealing with unrelenting worry became the predominant emotional

response.

> For the first little while you didn't sleep as well because you were worried about him having reactions at night time ... and it got to be kind of a daunting thing after a while ... worrying about meals...

The father also experienced role work and cognitive work that are characteristic of the reordering phase. His role work reflected the property of role expansion and beginning role satisfaction. He had redefined his role to include the diabetes and was making efforts to realize that goal. Cognitively, the father was at an apprentice level; he was capable of basic care but experienced difficulty with decision-making and problem-solving. He recognized that additional cognitive work would be necessary if he was to integrate the child's diabetes into his life.

In this phase, the father's role work was frequent and intense. The father left the hospital feeling capable of basic care and desiring an active role. However, continued role work was problematic because he missed many experiences while he was at work.

> I did go back [to work] ... that is when it probably got worse for me ... when I was doing things with my son, I wasn't as comfortable with his disease as my wife was ... I don't think that did good things for my son either.

The father used knowing/learning, redefining, and restructuring strategies to resolve this aspect of his role work. The father defined his expanded diabetes role as 'part-time' and restructured his work to ensure that he could take on evening and Saturday care. His continued participation in the diabetes care-taking tasks ensured that he was a capable care-provider.

The father's cognitive work supported this role work. At the beginning of this phase, the father described himself as a beginner; by the end of the phase, he described himself as an expert. The father was active in his cognitive work. He relied on formal (health professionals, literature, and a support group), and informal (wife, other parents), sources of information. He participated in a fluctuating, shared assistantship with his wife. That is, early in the reordering phase, the mother's knowledge surpassed the father's. At this time the mother tutored the father until he had an equivalent knowledge and skill level. This shared assistantship was followed by the father developing specialist level of knowledge and skill.

The role work and cognitive work also facilitated the father's emotional work related to unrelenting

worry. He related that his active role, and an 'expert' knowledge base provided him with a sense of control. This control lessened his worry. He stated: "And it is one of those things that eventually through doing, and through time, you just work your way through it. It got better".

The father's reordering phase was a time of active role work that was supported by cognitive and emotional work. The interaction between these three types of work promoted the father's advancement through this phase and his ultimate integration of the diabetes into his life.

Internalizing change.

The father entered this final phase of integrating once his patterns of living were established and accepted. The point in time of this progression was not definite: "I don't know, it just progressed by doing. Life goes on and you have to get on with it".

This father echoed the central characteristic of the internalizing phase; that is, the changes that have occurred because of the diabetes are no longer conscious or noticed. The father's life with the diabetes is his 'normal' life: "it is amazing that you

can accommodate everything that you could do before".

Cognitive work, emotional work, and role work could not be delineated as separate processes by the father. The father had a general view of the diabetes and himself; he had established an approach to living with the diabetes that was stable and did not require on-going active work. Emotionally, the father expressed acceptance of his child's condition. He was satisfied with his part-time role and did not suggest any need to alter his approach to parenting his chid, or supporting his wife. Cognitively, the father perceived himself as an expert; he sustained this level of capability through on-going diabetes care and self-learning.

In this case, the father's integration of the diabetes into his life has reached a point of stability and equilibrium.

Father B.: Suspended Reordering

The following case reflects the words and experiences of a father who had not yet attained integration. This father had difficulty with the reordering phase of integrating, and therefore, was unable to enter the phase of internalizing change.

Discovering the meaning of diabetes.

This father's experience in the discovering phase was similar to fathers who resolve the phases of integrating. This father experienced emotional responses characteristic of the property 'acknowledging the reality of diabetes'. The father's initial feelings were characterized by shock and disbelief. "It was quite a shock ... I was very upset ... I had a tough time dealing with it, right from the first instance; I really had trouble accepting". The father also described cognitive work that was typical of the stage of discovery. He spoke of participating in formal education sessions and in his child's diabetes care. His knowledge was at the apprentice stage; he was capable of performing care-taking tasks and shared in the care of his child. Properties of role work were

also described. The father experienced role extension and beginning role competence; he took time off work so that he could participate in diabetes education and the care of his child.

This father employed strategies for each type of integrating work. The father used cognitive and role work strategies in a way that was similar to fathers who had successfully integrated. For example, the cognitive strategies searching, acquiring, and experiencing were used by the father as he worked through the cognitive work of the apprentice stage. Role work included the strategies of knowing/learning and restructuring. The father was able to find a role for himself during his child's hospitalization.

This father's emotional work strategies were unlike other fathers. This father used fewer strategies, and his use of these strategies was limited. Possible emotional work strategies included normalizing, personalizing, and managing. The use of these strategies encompassed a single notion: the diabetes could only be accepted when it was cured. The father's normalizing strategies were limited to comparing diabetes to other diseases that could not be

'cured'. His personalizing strategy reflected difficulty accepting the diabetes; it was seen as a hopeless situation. "What happens today is going to happen today, and there is nothing you can do about it". Hopelessness, and waiting for a cure, were reflected in the father's managing strategy. "There is nothing we can do about it, except hope that they find a cure for it".

This father experienced the phase of discovering in a way that was similar to integrating fathers. Cognitive work included achieving an apprentice level of knowledge and skill. Role work included achieving role extension and early role competence. Emotional work included attempting to acknowledge the reality of the diabetes. This work was not resolved in the discovering phase; however, this was not unusual. All fathers extended the work of acknowledging the reality of the diabetes into the phase of reordering. What was different in this case, was the father's limited strategies for working through his emotional responses.

Reordering patterns of living.

The father began his phase of reordering patterns of living shortly following his child's discharge from

hospital. In this phase, the father conducted emotional, cognitive, and role work. Emotional work was dominant; cognitive work and role work were limited. For this father, the phase of reordering has continued for five years; emotional work is ongoing and cognitive and role work appear fixed.

During the reordering phase, the father's cognitive work was depicted as an assistant. Early in this phase, the father entered a equal, shared assistantship with his wife. "It was a learning process ... we both were reading the book and figuring it out and telling each other what was happening." Because of the father's work responsibilities, and limited capability, his equal assistantship soon became unequal: "she took over ... with my scheduling at work, I could be out for two or three days in a row ... so it just naturally evolved". The father never advanced his knowledge beyond the assistant level. He had limited sources of information and limited experience in caring for his child; he did not express any need to expand his knowledge base. The father's comments illustrate these characteristics of the 'assistant':

> I never learned it because I didn't have to ... but W. [wife] told me what to do and now I know how to do it. ... I'm not as comfortable changing her insulin; I would never even give it a try.

The father's role work involved the properties of continued role competence and role expansion. The father did not reflect on any conscious re-defining efforts. His role expansion was characterized by taking on a supportive role. This role was supported by his on-going, limited cognitive work and his perceptions of his career demands, and his wife. The father believed that his job limited his ability to take on an active role. He frequently stated: "I can't be counted on". His perceptions of his wife's role, and capabilities, also influenced his role expansion. "She is just super organized and she just does it and it's as simple as that. She says 'you do this' and I will do it. So I just do what I am told".

The father's emotional work became more complex and difficult during the reordering phase. While integrating fathers reported a gradual acceptance of the reality of diabetes, this father struggled with prolonged difficulty in acknowledging the reality of diabetes. He could not accept the diabetes and

continued to express disbelief: "I still have trouble accepting it. I still have trouble dealing with it ... you have a hard time understanding it".

The father's emotional work of acknowledging the diabetes was complicated by the introduction of the emotional work of unrelenting worry. The father expressed on-going and unresolved worry about future complications. "You know you read the stuff and you see the complications that can develop ... I worry about it an awful lot". The father also expressed unrelenting worry about his well child.

> Its incredible. Emotionally it is very upsetting. She [sibling] has discussed her frustration with other people, but not to us...I mean the sibling rivalry is incredible when there is diabetes, really incredible.

In the reordering phase, the father continued to rely on the strategies he developed in the discovering phase, that is, normalizing, personalizing, and managing. He also employed personal coping strategies to cope with his emotional work: he channelled his energies into other activities, and he repressed any feelings about the diabetes. Three times during the interview, the father admitted that he had never thought about his emotional responses and how he might

cope. The father also consistently reported that he felt that he did not have a source of diabetes support.

This father's process of integrating was stalled by unresolved emotional work. The phase of discovery was typical; however, the phase of reordering was dominated by emotional work. The predominance of this work may have limited the role and cognitive work characteristic of this phase.

In conclusion, because of the inter-dependence of the three types of work, difficulty with one type of work may inhibit the remaining two types of work. Advancement through the phases of integrating may be impeded unless all three types of work are used concurrently, and successfully.

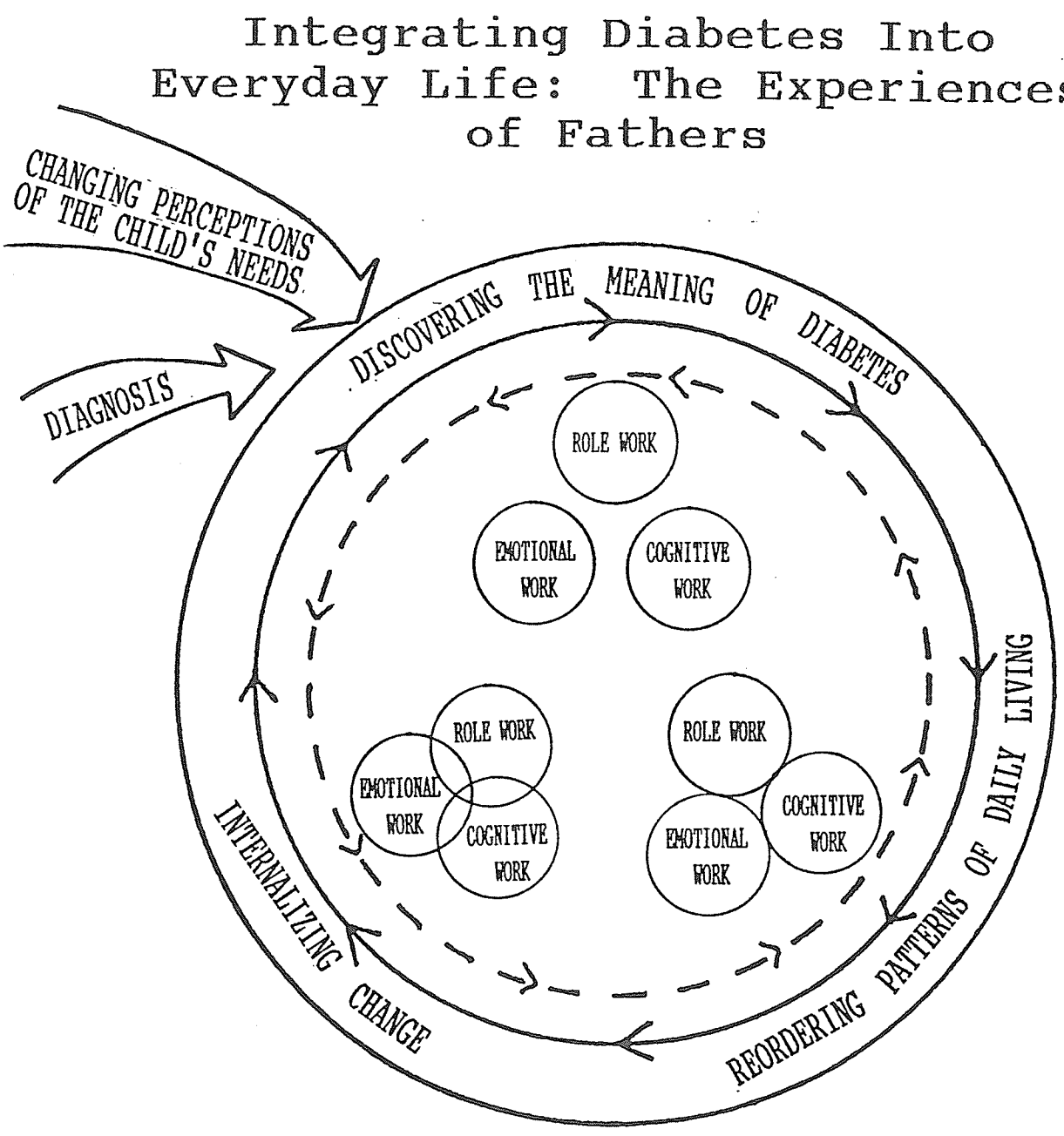
Integrating Diabetes into Everyday Life: The Experiences of Fathers

The basic psychosocial process identified in the substantive area of fathering a pre-adolescent child with IDDM has been articulated as "integrating diabetes into everyday life". The process of integrating refers to the father's assimilation of the diabetes into all aspects of his life. The diabetes is incorporated into the father's view of himself as a father and his everyday world. The impetus for this process of integrating is the father's evolving perception of his diabetic child's needs. Integrating diabetes into everyday life is represented by the father's advancement through three related, cyclical phases: discovering the meaning of diabetes, reordering patterns of daily living, and internalizing change. These phases are resolved through the father's use of energy to overcome and adapt to the specific challenges of each phase. The father's adaptive efforts can be described as work: emotional work, cognitive work, and role work; each occur concurrently throughout the three phases of integrating. Each phase is characterized by varying importance and properties of work; however,

each type of work must occur or integration may be stalled.

This substantive process theory of integrating allows for flexibility, individuality, and variability in the father's experiences with his child's diabetes. The phases, and work, of integrating are not time-limited, linear, or fixed. The father's movement through the phases, and his work in each of the phases is flexible and individualized. A model depicting the theory of integrating diabetes into everyday life is presented in Figure 6.

FIGURE 6


Integrating Diabetes Into Everyday Life: The Experiences of Fathers
CHANGING PERCEPTIONS OF THE CHILD'S NEEDS
DIAGNOSIS
DISCOVERING THE MEANING OF DIABETES
REORDERING PATTERNS OF DAILY LIVING
INTERNALIZING CHANGE
ROLE WORK
EMOTIONAL WORK
COGNITIVE WORK
ROLE WORK
EMOTIONAL WORK
COGNITIVE WORK
ROLE WORK
EMOTIONAL WORK
COGNITIVE WORK

CHAPTER SIX

DISCUSSION AND CONCLUSIONS

Introduction

An analysis of qualitative data led to the conceptualization of a beginning substantive process theory titled: Integrating Diabetes into Everyday Life: The Experiences of Fathers. In this chapter, a discussion of the substantive theory is presented in four sections. In the first section, the theory of integrating diabetes is discussed and the results of the study are related to other empirical and theoretical literature. In the second section, the research findings are connected to the conceptual framework of the study, symbolic interaction theory. Recommendations for research, practice, and education are proposed in the third section of the chapter. Finally, the chapter concludes with a summary of the research process.

Discussion of the Findings

The theory of integrating diabetes into everyday life articulates the processes through which a father assimilates his child's diabetes into all spheres of his life. Integrating diabetes is accomplished through the father's use of energy to achieve three types of work: emotional work, role work, and cognitive work. In each of these types of work, the father actively and intensely uses physical, emotional, and intellectual effort to achieve the tasks specific to the work. It is through this work, that the father is able to advance through the phases of integrating and successfully assimilate his child's diabetes into his life. In this section, the three types of work will be discussed and related to the empirical and theoretical literature.

Emotional Work

The category of emotional work referred to the father's awareness and use of energy to acknowledge the diabetes and adapt to its implications. The father's emotional work was effortful and continuous.

The emotional responses reported by fathers in

this study parallel those reported by Koski (1969) and Kovacs et al. (1985) in their studies of families of diabetic children. However, these authors also reported that acute emotional reactions were followed by a state of "acceptance" or "adaptation". In this study, titled "integrating diabetes into everyday life", the fathers did not "accept" their child's diabetes; rather, the reality of diabetes was accepted. This accepted-reality was an on-going process that was concurrent with a continuous state of worry that, like other emotional responses, lessened but did not completely disappear. This notion differs from the meaning implied in the term "acceptance" which reflects a linear, end stage progression toward a permanent stability.

The father's ability to conduct his emotional work was contingent on his perception of support. The number of actual supports was not critical; in fact, several fathers, who had successfully managed their emotional work, reported that their wife was their only source of support. Few studies have actually explored the father's perception of support. However, Jordan's (1990) study of fathering, and Kazak & Marvin's (1984)

study of families of children with spina bifida found that fathers' perceptions of the quality and effectiveness of their support were more important than the number of supports. This finding is significant; quantifying support networks may not capture the father's level of support and would do little to identify fathers at risk.

The fathers in this study managed their emotional work by using personalizing, normalizing, reality-reasoning, managing, and sharing strategies. Although terminology may vary, other literature has illustrated similar coping strategies. Chronic illness literature has suggested that both normalizing (Anderson, 1981; Anderson & Chung, 1982; Holaday, 1984; Krulik, 1980; Strauss & Glaser, 1975), and personalizing the illness (Holaday, 1984), may mitigate the emotional impact of an illness. Koski (1969) reported that fathers who adapted to their child's diabetes demonstrated behaviours that were consistent with the strategy of sharing.

The cognitive based strategies of reality-reasoning and managing have not been identified in illness related literature. However, Cook's (1988)

study of bereaved fathers indicated that father's grief management styles were often cognitively based and contained practical, concrete, rational and logical approaches that were similar to the strategies of reality-reasoning and managing. This finding in male subjects is not surprising; many authors have proposed that men and women differ qualitatively in their coping behaviours (Cook, 1988; Kovacs et al., 1985; McCubbin et al., 1983; Powers et al., 1986). Failure of illness literature to identify cognitive based "male" coping strategies may be due to limitations in coping measurements. For example, coping indices derived from maternal samples may not reflect the experiences of men, and therefore, research may have been unable to identify coping strategies that may be unique to men.

To summarize, the father's emotional work was reflected in an on-going process of acknowledging the reality of diabetes and dealing with unrelenting worry. Unlike a staged progression terminating with permanent acceptance, the father continuously worked to accept the changing reality of his child's needs. The father managed his emotional work by relying on support and carrying out a number of strategies.

Role Work

Role work referred to the intentional use of energy to define, organize, and enact the functions associated with fathering a child with diabetes. During role work, the father balanced his other roles while attempting to develop a diabetes role that was consistent with his own and his spouse's role expectations.

Three variables identified in role work have been reported in the general fathering literature: 1) the influence of role expectations; 2) the father's role competence; and 3) the father's role satisfaction. However, there is minimal research that examines the process of taking on a new role.

In the study of integrating diabetes, the father's and the mother's role expectations were the primary conditions of role work. Other literature has reported similar findings. Several authors have suggested that the father selects a child-care role that is consistent with his wife's expectations of him (Cowan & Cowan, 1987; Lewis & Sussman, 1986; Palkovitz, 1984; Reiber, 1976), while other research has suggested that the father's role with his child will resemble his already

established role preferences (Cowan & Cowan, 1987; McHale & Huston, 1984; Russell & Radin, 1983). Likely, the maternal and paternal factors influencing role work are multidimensional and interactive. The cross-sectional approach of this study and the general fathering literature, and the propensity of studies to measure a limited number of variables, have done little to illuminate this process. In addition, the enactment of roles for fathers of ill children has not been studied. However, the consistencies between the fathering literature and this study of fathers of children with diabetes suggests that parental expectations and interactions are important in the father's ultimate role work. Neither this study, nor other research, has clearly illustrated how these expectations interact and change through the family's life cycle.

The second concept of this study, role competence, has also been reported in the fathering literature. This literature suggests that fathers are able to participate in their well child's care only when they feel capable and competent (Baruch & Barnett, 1986; Entwisle & Doering, 1988; Hawkins & Belsky, 1989;

McHale & Huston, 1984; Partridge, 1988). These findings are congruent with the study of fathers of children with diabetes. Fathers required a sense of competence in a diabetes role prior to their enactment of a role. This finding suggests that the father's role work is more complex than simply selecting and adopting a new role. Developing a sense of competence is an integral component of the process.

The third concept of role work, role satisfaction, has received minimal attention in fathering literature. The fathers in this study attempted to find personal contentment in their role regardless of the level of their participation. In a general study of fathering, Radin and Sagi (1982) found that all fathers reported at least a moderate level of satisfaction in their fathering role. This general sense of satisfaction may have been an artifact of the quantitative measurement of satisfaction. However, a general satisfaction in fathering roles may be associated with the use of cognitive based coping strategies such as those demonstrated in this study. Men may appraise their situation using a reality-reasoning approach which allows them to develop a view that they are doing all

they can given their circumstances. Thus, a reality reasoning approach may allow men to find satisfaction regardless of their role.

This study demonstrated that taking on a new role is a complex, effortful, and interactive process. This finding is substantiated by Jordan's (1990) grounded theory study examining the processes of mens' role-making during pregnancy and early fatherhood. Jordan found that new fathers exerted considerable effort in taking on an involved parent role. This effort was influenced by the father's interactions with himself and his wife; his adoption of an actual role was consistent with his perception of his child's needs. The similarity between Jordan's findings and the study of integrating diabetes suggests that the fathers role work may be on-going. Role work may begin with pregnancy and evolve as the father's perception of his child's needs shifts throughout the child's life. Changing perceptions, and the resultant role work, may occur during normative periods of growth and development, as well as non-normative periods such as the diagnosis of an illness.

To summarize, the father exerts efforts to find

and enact a role in his diabetic child's life. Several variables identified in the study of integrating diabetes have been addressed in fathering literature. However, the focus on specific variables has not clearly illuminated the processes involved in the role work. The category of role work moves beyond the identification of specific variables. This research described some of the processes that the fathers experience in a diabetes role.

Cognitive Work

Cognitive work referred to the use of energy to develop a diabetes knowledge base and diabetes care-taking skills. This work was characterized in three properties: apprentice, assistant, and specialist. Cognitive work was contingent on the father's self-perception of capability.

Although no research was identified that documented the processes involved in the father's knowledge and skill development, the properties identified in cognitive work closely parallel Benner's (1984) model of nursing skill acquisition. Similar to the findings in this study, Benner's phenomenological

research demonstrated that knowledge and skill progress from: a reliance on theoretical principles, to the utilization of paradigms based on concrete experiences; a view of situations as a compilation of equally relevant parts, to a complete whole with only certain relevant parts; and a detached observer, to an involved performer (p. 13). Benner conceptualizes this process of advancing skill into five phases beginning with "novice" and ending with "expert". This model of skill acquisition is not unlike the model presented in this study. Benner's novice is consistent with the father's apprentice phase; the expert phase is congruent with the father's specialist phase. The consistencies are not surprising given that diabetes care involves the acquisition of complex theoretical information and practical skill. These parallels between nursing and parenting the child with diabetes demonstrate the intensity of home diabetes management and the considerable demands that are placed on the parents of a child with diabetes. The processes depicted in cognitive work and Benner's theory could provide a basis for assessing and guiding the father's cognitive work.

Properties of the father's cognitive work have been examined indirectly in studies that report paternal involvement in diabetes care-tasks. This literature has described knowledge and skills that are consistent with the apprentice or assistant level of cognitive work (Etzwiler & Sines, 1962; Wagner, 1987). This finding is inconsistent with the findings of the study of integrating diabetes. Fifty percent of the fathers in this study had achieved the specialist stage of cognitive work. The high level of specialists in this study may be due to characteristics of the sample (elite bias) or the ability of the qualitative approach to capture in more detail the complex characteristics of the father's cognitive work. Further study with more heterogenous sample may clarify this discrepancy.

Over-view of the Theory

Conceptualization of the categories of emotional work, role work, and cognitive work led to the development of the beginning substantive theory: Integrating Diabetes into Everyday Life: The Experiences of Fathers. This process of integrating was conceptualized as the advancement through three

cyclical and interdependent phases: discovering the meaning of diabetes; reordering patterns of daily living; and internalizing change. The impetus for the father's movement through these phases was his evolving perception of his child's needs. This movement was achieved through the emotional, role, and cognitive work that was characteristic of each phase. In order to achieve each phase, all types of work were required. The nature and degree of work changed; however, work was constant due to the unrelenting demands of diabetes and the changing nature of the child's needs.

The substantive theory of integrating diabetes was based on the experiences of fathers who had a child with insulin-dependent diabetes mellitus (IDDM). Although the data for this theory were derived from a homogenous sample of fathers, all fathers had not integrated their child's diabetes into their everyday lives to the same extent. This range in integrating experiences allowed for the presentation and analysis of a variety of fathering experiences.

The theory of integrating diabetes is only a beginning substantive theory. It depicts processes that represent the experiences of married, relatively

involved fathers of pre-adolescent diabetic children. A broad range of fathering types and behaviours were not sampled. For example, fathers who were disengaged, full-time care-givers, or absent did not participate in the study. Therefore, additional theoretical sampling is required to provide a more complete substantive theory of integrating diabetes into everyday life. However, this beginning theory of integrating diabetes is theoretically linked to other theories of coping and adaptation, chronic illness, and fathering.

The theory of integrating diabetes is conceptually linked to theories of coping and adaptation (Lazarus, 1966). Although the terminology and the level of specificity differ, the general processes articulated in the theory of integrating diabetes are conceptually linked to Lazarus' (1966) core concept, "appraisal". According to Lazarus' theory, individual's cope and adapt as a result of three appraisals that arise out of perceptions: primary appraisals, secondary appraisals, and reappraisals. Primary appraisal refers to a cognitive processes whereby the individual develops a perception of a threatening situation based on the situation itself and the psychological makeup of the

individual (Lazarus, 1966). Secondary appraisal refers to the individual's response to this perception; the possible range, and consequences, of coping actions are considered. Coping may be expressed in two ways: 1) through direct action on self or the environment; and 2) through intrapsychic processes which include attention deployment (tuning out of what is harmful or occupying the mind with positive thoughts), defensive reappraisal (developing benign or positive interpretations of events), and wish-fulfilling fantasies (Lazarus, 1966; Lazarus, Averill, & Opton, 1974). Finally, reappraisal refers to a change in the original perception which occurs as a result of coping processes and changing internal and external conditions (Lazarus et. al, 1974). To summarize these appraisals, the individual develops a perception of a threatening situation (primary appraisal); based on this perception, the individual develops a perception of the range, and consequences, of coping behaviours he/she may use (secondary appraisal). Finally, the individual changes or adjusts his/her perception of the situation. This new perception occurs as a result of the utilization of coping alternatives which produce

changes in internal and external conditions (reappraisal). Thus, the individual copes with a threatening situation by constantly appraising, employing coping strategies, and reappraising the situation. This process of appraisal is cyclical, on-going, and individualized.

The processes depicted in Lazarus' theoretical perspective (Lazarus, 1966; Lazarus et. al, 1974) can be applied to the findings of the study of fathers of children with diabetes. In a general sense, the primary appraisal that drives the father's coping and adaption is his perception of his child's needs. The secondary appraisal, or the range of coping behaviours, are depicted in the work of integrating and the strategies that are employed. That is, the fathers perception of the child's needs will determine the nature of his emotional work, role work, and cognitive work. On-going reappraisal occurs and is evident in the father's progressive use of work during the phases of discovering, reordering, and internalizing. In each of these phases, the father's reappraisal of his situation results in changing properties of emotional, role, and cognitive work.

The specific coping behaviours outlined in Lazarus' theory (Lazarus, 1966; Lazarus et. al, 1974) also provide broad theoretical labels for the strategies identified in the work of integrating. Lazarus' coping response of "direct action on self or the environment" is consistent with the emotional work strategies of managing, sharing, and all role work and cognitive work strategies. The coping expressed in "intrapsychic processes" parallels strategies identified in emotional work. Attention deployment, or tuning out what is harmful and emphasizing the positive, is consistent with reality-reasoning and components of normalizing. Defensive reappraisal, or developing a positive interpretation of events, is consistent with normalizing and personalizing strategies.

Although Lazarus' theory of coping and adaptation provides an articulation of general concepts and processes that were found in this study, it lacks specificity. An articulation of the father's experience with his child's diabetes could not be derived from this general theory and therefore, information required for the substantive area of

childhood diabetes is not readily available. Without this specific information, Lazarus' theory does not contain information that is necessary to guide practice in the area of childhood diabetes.

The theory of integrating depicts experiences that are both similar and dissimilar to theories of chronic illness. It is dissimilar to theories that propose that adaptation to illness is represented by a series of successive, linear stages that terminate with a state of permanent acceptance (Mattsson, 1972; Miller, 1968). Rather, this empirical study proposes that the work of integrating is continuous and cyclical. Although the father may reach the internalizing phase, resurgence of the work that is characteristic of earlier phases is likely due to changes in the father's perception of his child's needs. However, chronic illness literature also presents several concepts that are consistent with this empirical study. Other theoretical literature has emphasized processes and change, interactions inside and outside the family, and the on-going "tasks" or "work" that assists the individual in achieving a personal acceptance,

acknowledgement, or integration (Craig & Edwards, 1983; Futterman & Hoffman, 1973; Hymovich, 1976; Moos, 1984; Strauss & Glaser, 1975).

The theory of integrating diabetes is also linked to other general theories of chronic illness. Strauss and Glasers' (1975) theory describing the process of living with a chronic illness illustrates several experiences that are similar to the experiences of father's of children with diabetes (normalizing, illness and regime management, and restructuring social and personal activities). However, this theory emphasizes the ill, adult individual and does little to clarify the processes involved in fathering a child with diabetes.

The theory of integrating diabetes is closely linked with several concepts identified in Corbin and Strauss' (1988) grounded analysis of the experiences of couples living with a chronic illness. These authors identify the core category as unending work and care and delineate three categories of work: biographical, every-day, and illness-related. Each of these categories contain properties that are consistent with the properties of emotional work, role work, and

cognitive work. Corbin and Strauss also identify four properties of work that are consistent with the theory of integrating: work processes are mutually affecting; work processes depend on the individual and interactions with self and others; work process must be present in each situation if work is to go on; and one or another work process may be prominent at any given point in time (p. 130). The conceptual similarities of the theory of integrating diabetes and Corbin and Strauss' theory could allow for further elaboration of a substantive theory of caring for the chronically ill. This theory would move beyond care-giving to an adult family member by articulating the processes involved in caring for a chronically ill child.

The theory of integrating diabetes is also conceptually linked to theories of fathering. Jordan's (1990) theory of fathering illustrates several processes that are congruent with the processes identified in emotional work and role work. Jordan's theory of fathering could be linked to the theory of integrating diabetes by including childhood illness in the trajectory of fatherhood. For example, Jordan's

delineation of role-making ends with the concept of "parent"; this could be extended to include the fathering roles identified in the theory of integrating. Assimilation of the two theories would provide an expanded substantive theory of fathering both ill and well children.

Although links between the theory of integrating diabetes and other substantive theories have been emphasized, a formal theory of "integrating" could also be developed from this theory. Glaser and Strauss (1967) define formal theory as theory that is developed for a conceptual area of social inquiry. Rather than theory related to a specific empirical area, formal theory is more general and abstract. It is developed from substantive theory by expanding the comparative analysis to include many similar and dissimilar substantive areas (Charmaz, 1990; Glaser & Strauss, 1967). The theory of integrating diabetes could be moved to a formal theory of integrating by conducting comparative analysis of many substantive areas where integrating situations may be depicted. This would allow for the elaboration and abstraction of the

process of integrating. For example, parenting, marriage, career or education development, divorce, relocation, addition or deletion of family members, and illness diagnosis are substantive areas where integration may occur.

In summary, the theory of integrating diabetes describes the processes experienced by fathers who have a child with diabetes. This beginning substantive theory may be used to analyze a range of fathering experience. However, additional theoretical sampling is required to ensure that the processes depicted in this theory are experienced by all fathers of children with diabetes. In spite of this limitation, concepts in this theory are linked to other variables that have been articulated in the theoretical literature. With additional theoretical sampling and comparative analysis, the theory of integrating diabetes could be expanded to provide a substantive theory of adaptation to illness, chronic illness care, or fathering. Further sampling and analysis could also lead to the development of a formal theory of integrating.

Discussion of Findings Related to the Conceptual Framework

The theoretical basis for this study is symbolic interactionism. This broad, general theory proposes that human behaviour is shaped by the individual's construction of meanings and perceptions which arise out of social interactions. The findings of the research study will be related to this theory in the following section.

Symbolic interaction (SI) theory is based on three premises outlined by Blumer (1969). The first premise states that humans act toward things based on the meanings that the things have for them. The data supported this premise. The father's responses, and ultimate behaviours, were a result of two groups of meanings: the father's definition of his situation; and the father's view of himself. The father derived meanings regarding his situation by: defining the meaning of having a child with diabetes; defining his possible diabetes behaviours such as care-taking and parenting; defining possible situational barriers and facilitators; and defining his roles inside and outside

of the family. The father also ascribed meaning to his view of himself in terms of his level of support, competence and capability, and own roles such as husband, father, care-taker and supporter. The father's development of meanings in all of these areas influenced his over-all perception of his child's needs. It was this perception that influenced the intensity, range and nature of the father's experiences as he conducted his work.

The second premise of SI theory is that the meaning of things arises out of interactions between people. The data also supported this premise. The meanings that the father gave to his situation and himself were derived from interactions between himself and his family. For example, the wife's high or low, and positive or negative, expectations for the father's role influenced his role work. This perception, in turn, influenced his cognitive work. Interactions with individuals outside of the family also influenced the father's perceptions and meanings. His definition of the diabetes, diabetes care-taking tasks, and his view of himself as capable and competent were influenced by his interactions with health care professionals, family

members, friends, and other parents.

The third, and final premise of SI theory, is that meanings are developed and modified by a process of interpretation. This premise was supported by the data. The father interpreted and monitored his interactions with himself and others; personal meanings and perceptions were patterned from these interpretations. For example, the characteristics of the father's early role behaviours were the result of his interpretation of his own role as father. When the father developed a realization of the demands of diabetes, he monitored his past behaviours, interpreted others' (wife, health professionals) expectations of him regarding a diabetes role, and ascribed meaning to a diabetes role. Through interpretation of these factors, the father developed a view of what a satisfactory role would entail.

Although SI theory provides a comprehensive and applicable model for the analysis of the father's response to his child's diabetes, without the conceptualizations of this empirical study, it does not provide sufficient information to guide practice in this particular care situation. Thus, although the

general theory of symbolic interactionism supports the concepts and processes articulated in this study, it is too general to be useful in an applied discipline.

In summary, symbolic interaction (SI) theory was used as the theoretical basis of this study. Consistent with the findings of this empirical study and a symbolic interactionist perspective, the father of a child with diabetes developed perceptions, and ultimately behaviours, as a result of his interpretation of social interactions. Symbolic interaction theory provided the general framework from which the empirical data could be articulated and applied in clinical situations involving diabetes care.

Recommendations Arising From the Study

Recommendations for Future Research

Future research is required to increase the depth of the findings and to validate the theory of integrating diabetes into everyday life. The present study was based on a small, limited sample of fathers of pre-adolescent children with diabetes. The respondents in this study represented a relatively homogenous sample of middle-class and upper middle-class fathers. With the exception of one father, cultural groups other than Caucasians, were not represented in this sample. The sample was also restricted in terms of the age of the child. All children in the study were preschoolers at the time of their diagnosis; all, but one child, were school-aged at the time of the interview. In order to address these limitations, additional theoretical sampling is required in future research. Sampling should include a more representative group of fathers involved in a variety of fathering roles. Specifically, the same design could be used and theoretical sampling could be expanded to include: the responses of fathers with

diverse demographic features; a range in the age of the child at diagnosis; a variation in the child's duration of diabetes; a variation in father involvement styles; and a range of family constellations.

A second recommendation for future research would include research that addresses the applicability of the theory of integrating to other groups of fathers. Additional research could determine the extent to which this process of integrating occurs for all fathers. A similar study could be conducted with fathers: of children with other chronic illnesses, of acutely ill children, and of well children. This research approach would provide additional qualitative data that could lead to the development of a substantive theory of fathering.

Utilization of a longitudinal design in future studies could also be used to elaborate the process of integrating. This design may provide additional data regarding each of the three phases of integrating. For example, the father's discovering phase may be felt more acutely than was revealed by this retrospective study. A longitudinal design may also capture the father's response to structural or functional changes

in the family. This data could provide additional information regarding the indicators, time spans, and fluid nature of the phases of integrating.

This research demonstrated that the father's responses do not occur in a vacuum; interactions in the family, particularly with the mother, exert a strong influence on the father. Future research could address the couple's response to the diabetes. The experiences of the couple could be delineated by conducting a qualitative interview with each parent individually. Following analysis of individual data, a second interview could take place with the couple to clarify individual and family processes.

Finally, further research is required to address issues identified by the fathers in this study. First, research is required to address the concept of support. The fathers in this study identified support as a necessary condition for emotional adaptation; however, the nature of that support was not clearly elucidated. Research exploring the father's perceptions, and indicators of support could provide essential information for care-providers who are striving to assist fathers in their integrating work. Second,

research is required to address the role of health professionals. The fathers in this sample indicated that the role of health professionals was minor except during the newly diagnosed period. Research addressing health professional interventions is required to assess if there is a role for health professionals beyond the newly diagnosed period. Third, this study did not illustrate the effect of conflicting parental expectations on the father's integrating work. Research is required to determine the impact of congruent and incongruent parental expectations regarding the roles and responsibilities in diabetes care. Finally, research is required to address the concept of emotional work in greater depth. The fathers in this study relied on several cognitive strategies that have not been clearly identified in the literature. Research addressing the concept of coping in men may further elucidate the process of emotional work.

To summarize, additional research is required in order to understand fully the process of fathering a child with diabetes. Expanding this study with a more representative sample of fathers, and following the

fathers longitudinally, would allow for the validation and elaboration of the substantive theory. Development of a substantive theory of fathering may also be possible if future research addressed fathers of ill and well children. This study also portrayed several individual father, care-provider and family issues that require further research.

Recommendations for Nursing Practice

Fathers of a child with diabetes interact with nurses in a variety of settings. This study identifies several aspects of the father's experience that have a potential impact on nursing practice. Fathers are involved in an individualized, effortful, continuous, and complex process of integrating. They experience a range of emotional, role, and cognitive responses and use a variety of strategies that may not be documented in the popular, and theoretical, coping and chronic illness literature. Therefore, the processes identified in the theory of integrating could be used to inform nursing practice of the nature of the father's experience with childhood diabetes. Nurses need to acknowledge and respect the efforts that the father is

making and support him in his own unique response to his child's diabetes. Acknowledgement of the father's experience could do much to support him in all aspects of his work. Informing the family of possible paternal experiences may validate feelings, reduce conflicts, and assist with over-all family coping.

This theory supports the concept of family-centered diabetes care. Childhood diabetes impacts on fathers emotionally and socially; they are involved in deliberate attempts to integrate the diabetes into their lives. Therefore, a family-centered approach could validate the father's feelings and promote his integrating work. However, this theory also suggests that providers of family-centered care should not make assumptions regarding fathers' responses and participation in diabetes care. Fathers' responses and roles are diverse and reflect their individuality and their family circumstances and needs.

The fathers in this study indicated that nurses had the greatest impact on them during the newly diagnosed period. At this time, formal and informal education sessions assisted fathers with all aspects of their work. For many fathers, the importance of this

education was only realized retrospectively. Therefore, fathers should be encouraged to become involved in the education process. Education opportunities should be flexible enough so that the father can attend in spite of work responsibilities. Alternate arrangements should be made for those fathers who are unable to attend the structured education sessions. For example, education sessions may have to be conducted in the evenings or the in-patient nursing staff may have to assume responsibility for the father's education.

The findings of this study also demonstrate the importance of an initial, and ongoing, family assessment. Interactions with the family should be based on a comprehensive family assessment rather than pre-established assumptions regarding the father's response, roles, and knowledge. Specifically, assessment data should include:

1) identification of family member's roles, expectations, and level of satisfaction;

2) information on the primary influencing conditions (perception of support, perception of own and partners role expectations, perception of capability);

3) information regarding the characteristics and strategies of the father's emotional, role, and cognitive work;
4) determination of the phase of integrating (discovering, reordering, or internalizing); and
5) identification of any structural or functional changes that may influence integration work.
Compilation of this assessment data would provide health professionals with information that would allow for individualized, sensitive, and appropriate intervention strategies with the father and the family.

An additional recommendation for practice includes the development of interventions that are consistent with phases of integrating and the characteristics of the father's emotional, role, and cognitive work. For example, during the discovering phase, the father's role work may be dominated by a process of redefining which must occur prior to the father's adoption of a diabetes role. Interventions at this time would be directed toward assessing family member role expectations and determining what type of role the father is able to adopt. Interventions should also be based on an understanding of the interrelatedness of

emotional, role, and cognitive work; difficulty in one type of work may ultimately hinder other types of work.

A final recommendation involves extending nursing support beyond the hospital setting. A vast majority of the work of integrating occurs following discharge; therefore, an increased emphasis should be placed on long-term follow-up. Utilization of community health nurses immediately following discharge, combined with on-going follow-up in a diabetes clinic, could allow for support in the home environment, identification of barriers and facilitators unique to the family situation, and early identification of family strengths and weaknesses.

In summary, several recommendations for nursing practice arise from the study of integrating diabetes. The concepts and processes of this theory can be used to: sensitize nursing practice; promote appropriate assessment and intervention strategies; and structure care in many practice settings.

Recommendations for Nursing Education

Recommendations for nursing education parallel the recommendations made for nursing practice. The role of the father in health and illness is a little understood, and rarely addressed area. However, nurses in many settings will have the opportunity to work with the father of both ill and well children.

The theoretical processes involved in fathering should be included in family nursing curriculum. Fathering could be addressed in discussions of family theories such as developmental theory, or systems theory. Normative theories, such as Jordan's (1990), could be used to explore the processes in the father's role work with a well child. The processes involved in fathering during illness could be introduced as part of a trajectory of fathering.

Further development of nursing knowledge could be promoted in clinical practice. Concepts from a variety of clinical settings could be linked in order to explore fathering processes. For example, fathering experiences during childbirth and early parenting could be compared and contrasted to fathering experiences during a paediatric hospitalization.

An understanding of the processes of fathering a child with diabetes could be derived in clinical practice situations. Nursing students could be provided with an opportunity to follow a family who had a child diagnosed with diabetes. Attention to the father's responses and processes of integrating could be emphasised by the use of several bodies of literature such as coping and adaptation, chronic illness, teaching/learning, and home care.

Education of nurses must also emphasize general concepts arising from this study. There is great variability regarding the father's response to his child's diabetes. Societal, and health care professionals' expectations regarding the expanded role of the father may simply reflect an ideology rather than practice. Nurses require education that emphasizes the assessment of the family and acceptance of family values and roles and responsibilities.

To summarize, fathering processes are an essential component in nursing education. Expansion of curriculum to include fathering, and inclusion of fathers in clinical practice, could promote an understanding of the nature of fathers' experiences.

Summary of the Research Process

The purpose of this study was to explore and describe the processes through which the father assimilates his child's diabetes into his life. This research was motivated by a lack of clarity regarding the father's experiences, and a health care approach that dictates father involvement in diabetes care. A grounded theory approach was selected to describe qualitatively the father's experiences. Through theoretical sampling, and constant comparative data analysis, a beginning substantive process theory was derived.

The basic psychosocial process experienced by fathers of a child with diabetes is identified as integrating diabetes into everyday life. This process is individualized, multifaceted, and occurs over time as the father progressively, and often repeatedly, overcomes three related and interdependent phases: discovering the meaning of diabetes; reordering patterns of daily living; and internalizing change. The father's ability to move through, and sustain, the phases of integrating is neither automatic nor

guaranteed. Integration requires active and intentional efforts that involve emotional, role, and cognitive work. The impetus for this work is the father's evolving perception of his child's needs.

Other theories are linked conceptually to the theory of integrating diabetes; however, this theory is unique in that it offers a beginning conceptualization of the processes, rather than the variables, involved in fathering a child with diabetes. Although only a beginning theory with sampling limitations, this theory provides a framework from which the experiences of fathers can be explored and described.

Conclusion

In this chapter, the theory of integrating was reviewed and discussed. Parallels were drawn between this theory and other empirical and theoretical literature. Several recommendations for research, practice, and education were made. The chapter concluded with a summary of the research process.

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APPENDIX A

PRELIMINARY LETTER TO CANADIAN DIABETES ASSOCIATION REGARDING ACCESS

April 4, 1990
Kathy Thomson
1666 Mathers Bay West
Winnipeg, Manitoba
R3N 0T7
(204) 489-2221

Mr. Doug Sabourin
Executive Director
Canadian Diabetes Association
1091 West 8th. Avenue
Vancouver, British Columbia
V6H 2V3

Dear Mr. Sabourin:

Subject: Research study entitled: Childhood Diabetes: An Exploration and Description of the Father's Experience

As I discussed with you, I am a Graduate student in the School of Nursing, University of Manitoba, Winnipeg Manitoba; I will be moving to the Vancouver area in May, 1990. I have completed my course work and am presently preparing to conduct my thesis research . I am planning to conduct a study to examine the process through which fathers' integrate their child's diabetes into their lives. I am seeking access to fathers of children with diabetes through your agency.

My research is being supervised by three faculty members at the University of Manitoba. Professor Karen Chalmers is the chairperson of my thesis committee. She may be contacted in writing at the School of Nursing, University of Manitoba, Winnipeg, Manitoba, R3T 2N2, or by telephone at 204-474-9315. Dr. Alice Jope, Adjunct Professor at the School of Nursing at the University of British Columbia will be acting as my advisor in Vancouver. She may be reached, in writing, at University Hospital, 2211 Westbrook Mall, Vancouver, V6T 2V5, or by telephone at 604-228-7714.

My research will be exploratory and descriptive in nature. I am interested in understanding the process through which fathers' integrate the care of their child's diabetes into their lives. I would like to gain an understanding from the father's perspective and

therefore am interested in gathering this information directly from the fathers.
Men volunteering for the study must:
1. be the father of a child less than 13 years of age who has had insulin-dependent diabetes mellitus longer than 1 year,
2. be able to read, write, and speak English,
3. be living with his child who has diabetes,
4. have a telephone in order to arrange interviews.
5. live within 30 miles of the city of Vancouver

Each father participating in the study will be asked to complete a demographic information sheet and participate in an interview for approximately 1 to 1 1/2 hours. The interviews will be tape recorded. All information collected will be kept confidential. Participation in the study is voluntary; the father may withdraw from the study at any time. Prior to conducting the interview, the study will be explained to the father and he will be asked to sign a consent.

I am approaching your agency because of your involvement with families of children with diabetes. I would like to request access to fathers of children with diabetes through your agency's membership list. In order to ensure your memberships' confidentiality, I would ask that your office forward a letter outlining the research and requesting fathers' participation in the study. This process will not involve any direct costs to your agency; I will provide the letters, stationary, and postage. An indirect cost would be the staff time required to generate a mailing list and affix address labels to the letters. I would be willing to acknowledge the support of the CDA on any publications relating to the study and provide you with a summary report of the research.

I will be submitting my research proposal to my thesis committee and the University of Manitoba Ethical Review Committee in June, 1990. Once my proposal has been approved by both my thesis committee and the Ethical Review Committee, I will make a formal request for access through your agency. I will include a copy of my proposal and documentation of ethical approval at that time.

Thank you for considering this request. If you have any questions or concerns please do not hesitate to call. I look forward to receiving your response.

Sincerely,

Kathy Thomson R.N., B.N.

APPENDIX B

LETTER TO EXECUTIVE DIRECTOR OF THE CANADIAN DIABETES ASSOCIATION IN BRITISH COLUMBIA: FORMAL REQUEST FOR ACCESS TO SUBJECTS

Kathy Thomson
10448 Glenmoor Place
Surrey, British Columbia
V3R 9L1
(604) 583-5764

Mr. Doug Sabourin
Executive Director
Canadian Diabetes Association
1091 West 8th. Avenue
Vancouver, British Columbia
V6H 2V3

Dear Mr. Sabourin:

Subject: Research study entitled Childhood Diabetes: An Exploration and Description of the Father's Experience

I am a Graduate student from the School of Nursing, University of Manitoba, Winnipeg Manitoba. I have moved to the Vancouver area and am planning to conduct my thesis research here. I had made a preliminary request to you on April 4, 1990 requesting access to subjects through the Canadian Diabetes Association's membership list.

As we have discussed, my research is being supervised by three faculty members at the University; Professor Karen Chalmers is the chairperson of my thesis committee. She may be contacted in writing at the School of Nursing, University of Manitoba, Winnipeg, Manitoba, R3T 2N2, or by telephone at 204-474-9315. Dr. Alice Jope, Adjunct Professor at the School of Nursing at the University of British Columbia will be acting as my advisor in Vancouver. She may be reached, in writing, at University Hospital, 2211 Westbrook Mall, Vancouver, V6T 2V5, or by telephone at 604-228-7714.

My research study is exploratory and descriptive in nature; it will be examining, from the father's perspective, the process through which fathers' integrate the care of their child's diabetes into their lives. I would like to conduct intensive interviews

with approximately 10 fathers who have a child with insulin-dependent diabetes mellitus. Fathers who would be participating in this study would have to meet the following criteria:
1. be the father of a child less than 13 years of age who has had insulin-dependent diabetes longer than 1 year,
2. be able to read, write, and speak English,
3. be living with his child who has diabetes,
4. have a telephone in order to arrange interviews.
5. live within 30 miles of the city of Vancouver

As I outlined in my original letter, I would like to gain access to potential participants through the Canadian Diabetes Association's (CDA) membership list. I have written a letter requesting the father's participation in my study; I would ask that it be mailed to families on your membership list. In this way, CDA's membership information would be kept confidential. This mailing will not involve any direct cost to your agency; I will provide the letters, stationary, and postage. An indirect cost would be the staff time required to generate a mailing list and affix address labels to the letters. I would be willing to acknowledge the support of the CDA on any publications relating to the study and provide you with a summary report of the research.

My research project has been approved by my thesis committee and by the Ethical Review Committee at the University of Manitoba. I am enclosing documentation to support this approval. I have also enclosed a copy of my research proposal for your review.

I would like to meet with you so that we may discuss my research project. Please call me at any time and we can arrange to meet. Thank you for considering this request. I look forward to meeting with you.

Sincerely,

Kathy Thomson B.N.

APPENDIX C

LETTER TO BE SENT TO POTENTIAL RESEARCH PARTICIPANTS THROUGH THE C.D.A. VANCOUVER OFFICE

FATHERS OF CHILDREN WITH DIABETES: RESEARCH SUBJECTS NEEDED

This letter has been sent to you through the Vancouver office of the Canadian Diabetes Association. The office agreed to mail this letter to families on their membership list. No information from your C.D.A. membership file has been released to me.

My name is Kathy Thomson. I am a Master's of Nursing student at the University of Manitoba and have recently moved to the Vancouver area. I have been involved in nursing of children and families for the past fourteen years; I have been working exclusively with families of children with diabetes for the past 5 years. Throughout this time, I have been interested in promoting the health of families who care for children with long term illness. This letter is a request for your participation in a research study I am conducting.

My studies in Nursing have two major requirements. One is course work and the second is research. I have completed the required course work and am now beginning my research. I am being supervised by three faculty members at the University of Manitoba in Winnipeg Manitoba. Professor Karen Chalmers is my research advisor in Winnipeg; she may be reached at (204) 474-9315. Dr. Alice Jope is my advisor in the Vancouver area; she may be reached at (604) 228-7714. The Canadian Diabetes Association is in no way involved in this research other than mailing out this notice.

For my research, I have elected to study the process through which a father integrates the care of his child's diabetes into his life. Fathers who participate in this study will be asked to participate in an interview. All information will be kept confidential.

Men volunteering for the study must:

1. be the father of a child less than 13 years of age who has had Insulin-dependent diabetes more than 1 year,
2. be able to read, write, and speak English,
3. be living with his child who has diabetes,

If you are interested in participating, or have any questions about the study, please call me at 583-5764. Thank you for your consideration of this request.

Sincerely,
Kathy Thomson R.N.
Masters Student
University of Manitoba

APPENDIX D

WRITTEN AND TELEPHONE EXPLANATION OF THE STUDY

Hello, my name is Kathy Thomson. Thank you for your interest in my research study. As I discussed in my letter, I am a Master's of Nursing student and am conducting a study of how fathers integrate the care of their child with diabetes into their lives. As you know, this study will be supervised by three faculty members at the University of Manitoba in Winnipeg and one research advisor in Vancouver.

I would like to describe to you the purpose, method, and risks involved in the research. If you have any concerns or questions, please do not hesitate to ask me.

Any man who participates in this study will be asked to participate in an interview that will be tape recorded and fill out a sheet that asks for background information about his family. The interview will take approximately 1 to 1 1/2 hours; if you would like, we could have the interview over 2 sessions. I may also need to contact you a second time by telephone in order to clarify any questions that I have after reviewing the interview.

This research does not involve any direct risk to either you or your family. If you are uncomfortable with any of the questions or topics you may refuse to answer, withdraw from the study, or ask to have the tape recorder turned off.

Following our interview, notes will be made from the tape recordings. Your name will not appear on the tapes or on the transcribed notes; a code number will be used to identify the information gathered. The tapes and transcriptions, and name and code number combinations, will be kept in separate locked areas. My research supervisors may read the interview notes but your identity will not be revealed. At the end of the study, I will erase the tapes.

This study, or parts of it may be published; however, it will be written in a manner so that your statements could not be linked to you.

Your involvement in this study is voluntary. You may withdraw at any time without any risk to the care that your child or your family receives. If you agree to participate, you will be asked to sign a consent. You may also receive a written summary of the research if you like.

Do you have any questions about the study at this time? If you are interested, I would like to review the requirements for the fathers in my study. In order to volunteer for the study, you must: be the father of a child who is less than 13 years of age and has had insulin-dependent diabetes for at least 1 year; be living with this child; and live within 30 miles of Vancouver.

If you are interested in participating, I would like to arrange to meet with you at a time and place that is convenient for you.

Thank you for your time and consideration. If you have any questions or concerns, please feel free to ask me.

Kathy Thomson R.N. (604) 583-5764

APPENDIX E

INTERVIEW GUIDES

INTERVIEWS: 100, 110:

1. Lets go back to the time when your child was diagnosed with diabetes. What was that like for you? [PROBES: What were your feelings at the time?; what did having a child with diabetes mean to you?; what were your thoughts about your child's needs at that time?]

2. Thinking back to those early days, can you describe what your child's needs were and how you managed them? [PROBES: What was a typical day like for you then?; What sort of things had to happen in your family?; What was the easiest/most difficult thing for you?]

3. Can you tell me how other people responded to you at the time and what that was like for you?

4. As you look at things from the past and now, what are some of the changes that have occurred in your life? [PROBES: financial; time; relationship with children, wife, friends; leisure, travel].

5. What do these changes mean to you?

6. We have been talking about how things are for you right now. I wonder if you can describe for me what a typical day is like for you now?

7. How do you feel about this typical day?

8. You have told me how other people were during the diagnosis. What are they like now and how is that for you?

9. Are there benefits or positive aspects of this experience?

10. What has it meant for you to have a child with diabetes?

11. We have talked about the past and the present; I wonder if we could talk about the future for a few minutes. How do you see the future?

12. If you met a father on the street tonight who had a child who was just diagnosed with diabetes, what would you tell him?

13. Are there other things you would like to tell me which we have not discussed?

INTERVIEWS: 120, 130

1. Lets go back to the time when your child was diagnosed with diabetes. What was that like for you? [PROBES: What were your feelings at the time?; what did having a child with diabetes mean to you?; what were your thoughts about your child's needs at that time?]

2. Thinking back to those early days, can you describe what your child's needs were and how you managed them? [PROBES: What was a typical day like for you then?; What sort of things had to happen in your family?; What was the easiest/most difficult thing for you? ** (NEW PROBE: **How would you describe the health professionals response to you?**)]

3. Can you tell me how other people responded to you at the time and what that was like for you?

4. As you look at things from the past and now, what are some of the changes that have occurred in your life? [PROBES: financial; time; relationship with children, wife, friends; leisure, travel].

5. **[**DELETE PREVIOUS Q.5] Can you tell me how you and your wife decided on how each of you would participate in the diabetes care?**

6. We have been talking about how things are for you right now. I wonder if you can describe for me what a typical day is like for you now?

7. [**DELETE PREVIOUS Q.7] **How did you get from the point where you were at during the diagnosis to where you are today?**

8. You have told me how other people were during the diagnosis. What are they like now and how is that for you?

9. Are there benefits or positive aspects of this experience?

10. What has it meant for you to have a child with diabetes?

11. We have talked about the past and the present; I wonder if we could talk about the future for a few minutes. How do you see the future?

12. **[NEW QUESTION] Some fathers have told me that about 1 year following diagnosis, their child seems to come to accept that he/she has diabetes? Can you tell me if that has been your experience with your own child?**

13. [NEW QUESTION] **One of the things that I am interested in the father's role in the family. Can you describe your role as the father before you had a child with diabetes and then after your child was diagnosed?**

14. If you met a father on the street tonight who had a child who was just diagnosed with diabetes, what would you tell him?

15. Are there other things you would like to tell me which we have not discussed?

INTERVIEWS: 140, 150

1a. Lets go back to the time when your child was diagnosed with diabetes. What was that like for you? [PROBES: What were your feelings at the time?; what did having a child with diabetes mean to you?; what were your thoughts about your child's needs at that time?]

1b. [NEW QUESTION] **Some fathers have told me that they missed much of the education when their child was diagnosed because of work responsibilities. Was this the case for you? Ideally, what would you have liked your involvement to be at this time?**

2. Thinking back to those early days, can you describe what your child's needs were and how you managed them? [PROBES: What was a typical day like for you then?; What sort of things had to happen in your family?; What was the easiest/most difficult thing for you? How would you describe the health professionals response to you?]

3. Can you tell me how other people responded to you at the time and what that was like for you?

4. As you look at things from the past and now, what are some of the changes that have occurred in your life? [PROBES: financial; time; relationship with children, wife, friends; leisure, travel].

5. Can you tell me how you and your wife decided on how each of you would participate in the diabetes care?

6. We have been talking about how things are for you right now. I wonder if you can describe for me what a typical day is like for you now?

7. How did you get from the point where you were at during the diagnosis to where you are today?

8. You have told me how other people were during the diagnosis. What are they like now and how is that for you?

9. Are there benefits or positive aspects of this experience?

10. What has it meant for you to have a child with diabetes?

11. We have talked about the past and the present; I wonder if we could talk about the future for a few minutes. How do you see the future?

12. Some fathers have told me that about 1 year following diagnosis, their child seems to come to accept that he/she has diabetes? Can you tell me if that has been your experience with your own child?

13. [change focus of question] **One of the things that I am interested in the father's role in the family. Can you describe your role as the father before you had a child with diabetes and then after your child was diagnosed?**

14. If you met a father on the street tonight who had a child who was just diagnosed with diabetes, what would you tell him?

15. Are there other things you would like to tell me which we have not discussed?

INTERVIEWS: 160, 170,

1. [NEW QUESTION] I wonder if we could start at the time just before your child was diagnosed. Could you describe your family and the things you were doing at that time? [PROBES: your jobs, your children, your interests and leisure activities].

2. Now, could we go back to the time when your child was diagnosed with diabetes. What was that like for you? [PROBES: What were your feelings at the time?; what did having a child with diabetes mean to you?; what were your thoughts about your child's needs at that time?]

3. Some fathers have told me that they missed much of the education when their child was diagnosed because of work responsibilities. Was this the case for you? Ideally, what would you have liked your involvement to be at this time?
[**NEW PROBE: What are the effects when a father is or is not involved at this time?**

4. Thinking back to those early days, can you describe what your child's needs were and how you managed them? [PROBES: What was a typical day like for you then?; What sort of things had to happen in your family?; What was the easiest/most difficult thing for you? How would you describe the health professionals response to you?]

5. Can you tell me how you and your wife decided on how each of you would participate in the diabetes care?

6. [NEW QUESTION] Some fathers have told me that they are involved with their child with diabetes and have an important role in the family, but that what they do is very subtle. What do you think about that?
[PROBES: How does a father find his role with a child with diabetes; do you think others realize the father's role in the family?]

7. [NEW QUESTION] If your wife was here, and I asked her to describe your involvement in your child's care and your role in the family, what do you think she would tell me? [PROBES: Would you agree with your wife's view? If not why not?]

8. As you look at things from the past and now, what are some of the changes that have occurred in your life? [PROBES: financial; time; relationship with children, wife, friends; leisure, travel, **how people respond to you**].

9. Are there benefits or positive aspects of this experience?

10. What has it meant for you to have a child with diabetes?

11. You have talked about many changes with me; how did you get from the point where you were at during the diagnosis to where you are today?

12. [NEW QUESTION] If this was an ideal world and a father of a child with diabetes could have whatever he needed, what would he need to help him with this experience?

13. We have talked about the past and the present; I wonder if we could change our focus and talk about the future for a few minutes. How do you see the future?

14. If you met a father on the street tonight who had a child who was just diagnosed with diabetes, what would you tell him?

15. Are there other things you would like to tell me which we have not discussed?

ATTEND TO DATA AND PROBE RE:

A) The father's involvement in newly diagnosed education - facilitators, barriers, perceptions of, wife's response to, child's age and...
B) Interactions, communication, decision-making with spouse that may contribute to the father's involvement, perception of competence, knowledge re diabetes... That is, does the mother's response either facilitate or obstruct the father's involvement and sense of competence?
C) Does the mother's participation in the work force at the time of diabetes and during the years following influence the father's integration and experiences?

INTERVIEWS: 180

1. I wonder if we could start at the time just before your child was diagnosed. Could you describe your family and the things you were doing at that time? [PROBES: your jobs, your children, your interests and leisure activities].

2. Now, could we go back to the time when your child was diagnosed with diabetes. What was that like for you? [PROBES: What were your feelings at the time? what were your thoughts about your child's needs at that time?]

3. Some fathers have told me that they missed much of the education when their child was diagnosed because of work responsibilities. Was this the case for you? Ideally, what would you have liked your involvement to be at this time?
[PROBE: What are the effects when a father is or is not involved at this time?

4. Thinking back to those early days, can you describe what your child's needs were and how you managed them? [PROBES: What was a typical day like for you then?; What sort of things had to happen in your family?]

5. Can you tell me how you and your wife decided on how each of you would participate in the diabetes care?

6. [NEW QUESTION] **What part do you think your wife played in terms of your getting involved in the care of your child?**

7. Some fathers have told me that they are involved with their child with diabetes and have an important role in the family, but that what they do is very subtle. What do you think about that?
[PROBES: How does a father find his role with a child with diabetes; do you think others realize the father's role in the family?]

7. If your wife was here, and I asked her to describe your involvement in your child's care and your role in the family, what do you think she would tell me?
[PROBES: Would you agree with your wife's view? If

not why not?]

[DELETE PREVIOUS QUESTIONS 8, 9, 10]
8. How does a father get from the point that you were at during the diagnosis to the point where you are now? [PROBE: What sort of things have to happen for a father to work through the diabetes?]

9. If you met a father on the street tonight who had a child who was just diagnosed with diabetes, and he asked you what was going to be the largest challenge that he would face, what would you tell him?

10. If this was an ideal world and a father of a child with diabetes could have whatever he needed, what would he need to help him with this experience?

11. Are there other things you would like to tell me which we have not discussed?

CONTINUE TO ATTEND TO DATA AND PROBE RE:

A) The father's involvement in newly diagnosed education - facilitators, barriers, perceptions of, wife's response to, child's age and...

B) Interactions, communication, decision-making with spouse that may contribute to the father's involvement, perception of competence, knowledge re diabetes... That is, does the mother's response either facilitate or obstruct the father's involvement and sense of competence?

C) Does the mother's participation in the work force at the time of diabetes and during the years following influence the father's integration and experiences?

INTERVIEWS: 190

1. I wonder if we go back to the time when your child was diagnosed with diabetes. What was that like for you? [PROBES: What were your feelings at the time? what were your thoughts about your child's needs at that time?]

2. Some fathers have told me that they missed much of the education when their child was diagnosed because of work responsibilities. Was this the case for you? Ideally, what would you have liked your involvement to be at this time?
[PROBE: What are the effects when a father is or is not involved at this time?

3. Thinking back to those early days, can you describe what your child's needs were and how you managed them? [PROBES: What was a typical day like for you then?; What sort of things had to happen in your family?]

4. Can you tell me how you and your wife decided on how each of you would participate in the diabetes care?

5. What part do you think your wife played in terms of your getting involved in the care of your child?

6. Some fathers have told me that they are involved with their child with diabetes and have an important role in the family, but that what they do is very subtle. What do you think about that?
[PROBES: How does a father find his role with a child with diabetes; do you think others realize the father's role in the family?]

7. If your wife was here, and I asked her to describe your involvement in your child's care and your role in the family, what do you think she would tell me?
[PROBES: Would you agree with your wife's view? If not why not?]

8. How does a father get from the point that you were at during the diagnosis to the point where you are now?
[PROBE: What sort of things have to happen for a father to work through the diabetes?]

8a. [NEW QUESTION] **I wonder if you could tell me how you feel about were you are today. On a scale of 1 to 10, with 1 being very dissatisfied, and 10 being very satisfied, where would you place yourself?**

9. If you met a father on the street tonight who had a child who was just diagnosed with diabetes, and he asked you what was going to be the largest challenge that he would face, what would you tell him?

10. If this was an ideal world and a father of a child with diabetes could have whatever he needed, what would he need to help him with this experience?

11. Are there other things you would like to tell me which we have not discussed?

CONTINUE TO ATTEND TO DATA AND PROBE RE:

A) The father's involvement in newly diagnosed education - facilitators, barriers, perceptions of, wife's response to, child's age and...

B) Interactions, communication, decision-making with spouse that may contribute to the father's involvement, perception of competence, knowledge re diabetes... That is, does the mother's response either facilitate or obstruct the father's involvement and sense of competence?

C) Does the mother's participation in the work force at the time of diabetes and during the years following influence the father's integration and experiences?

INTERVIEW: VALIDATION OF THEORY

I have written a brief summary of my research findings and was wondering if you could take the time to discuss them with me. I would like go over a summary of my research and perhaps we could talk about it. What I am interested in is your view of this theory and if you believe it accurately portrays the father of a child with diabetes. Please remember that the data has been analyzed to present an abstract view of the father's experiences, therefore a lot of detail will appear to be missing.

1. Do you think that the father adapts to the diabetes over time and through stages similar to the stages of discovering, reordering, and internalizing?
PROBES: Is the progression sequential?

2. What do you think about the 'work'. Does the word 'work' reflect your experiences? Do you think that there was emotional, role, and learning work in your experience?

3. How do you think a father works through the emotional work, cognitive work, and role work? Does my analysis of the data reflect your experience?

4. What things are important for a father to conduct this work?
PROBES: What factors influence how the father adapts and works through his child's diabetes?

5. Is there anything else that you would like to add or change in this theory.

APPENDIX F

DEMOGRAPHIC DATA

DEMOGRAPHIC DATA

CODE # _____

Please answer the following questions. Please omit any questions that you do not choose to answer.

1. What is the age and sex of your child who has diabetes? _____

2. What is (are) the age and sex of your other children?

_____

3. When was your child diagnosed with diabetes? _____

4. What is your age? _____ What is your partner's age? _____

5. What is your occupation? _____

   Full time _____ Part time _____

6. What is your partner's occupation? _____

   Full time _____ Part time _____

7. What is your highest education level achieved?

   less than high school ____
   high school diploma ____
   community college/vocational diploma _____
   undergraduate degree _____ graduate degree ____
   none of the above _____

8. What is the highest education level of your partner?

   less than high school___
   high school diploma ____
   community college/vocational diploma _____
   undergraduate degree _____ graduate degree____
   none of the above _____

APPENDIX G

CONSENT FORM

CONSENT FORM

I _____, volunteer to participate in this study. I have been provided with, and have read, a written explanation of the study.

Kathy Thomson, R.N., a Master's of Nursing student in the School of Nursing, University of Manitoba, Winnipeg Manitoba, is conducting a study in order to describe the process through which fathers integrate the care of a child with diabetes into their lives. This study will be supervised by Professor Karen Chalmers at the University of Manitoba School of Nursing; her telephone number is (204) 474-8202. Ms. Thomson's advisor in Vancouver is Dr. Alice Jope; she may be reached at (604) 228-7714.

I understand that I will be interviewed once or twice by Kathy Thomson for 1 to 1 1/2 hours about my experiences as a father of a child with diabetes. These interviews will occur at a time and place convenient to me and will be tape recorded. I will also be asked to fill out a short form with background information about myself and my family. Kathy Thomson may contact me by telephone following the interview in order to clarify any questions she has following her review of the interview.

I understand that only the researcher will have access to my name and any identifying data. My name will not be used on the transcribed data, the study, or any publications related to the study. The interview tapes and notes will be identified by number only, and no one will have access to the name and number combinations except the researcher. This information and the tapes will be kept in separate areas that are locked and secure. The interview tapes will be transcribed; the

researcher and her thesis committee members will have access to this information. The tape recordings will be erased following the completion of the study.

I understand that this study has no direct benefits to me, however, hopefully this information may help nurses understand how childhood diabetes affects the father. I am free to stop the interview at any time; I have the right to refuse to answer specific questions or ask to have the tape recorder turned off.

Findings from this study will be summarized and may be published, however, my name will not appear in writings. I may receive a summary of the results of the study if I so desire. The Canadian Diabetes Association will not be provided with any information regarding the identity of the participants in this study; they will receive a summary report.

I may call Kathy Thomson, by telephone, at (604) 583-8764 or by writing her at 10448 Glenmoor Place, Surrey, B.C., V3R 9L1 during the course of the study.

I understand that participation in this study is voluntary. I am free to refuse to be in this study or withdraw at any time without any effects on the care of my child or my family.

I have received a copy of this consent form for my records. My signature signifies my agreement to participate in this study under the terms above.

Date	Participant	Researcher

I would like to receive a summary report of the research:

No _____

Yes _____

Please mail the summary to:

Name: _____

Address: _____

_____

APPENDIX H

ETHICAL APPROVAL FROM UNIVERSITY OF MANITOBA

ETHICAL REVIEW COMMITTEE

The University of Manitoba

SCHOOL OF NURSING

ETHICAL REVIEW COMMITTEE

Proposal Number N#90/13

Proposal Title: "Childhood Diabetes: An Exploration and Description of the Father's Experience."

Name and Title of Researcher(s): Kathryn Thomson
Master of Nursing
University of Manitoba

Date of Review: June 04, 1990

Decision of Committee: Approved: July 16/90 Not Approved: _____

Approved upon receipt of the following changes:

APPROVED WITH CHANGES SUBMITTED ON JUNE 29th, 1990.

Date: July 16, 1990

Theresa George, RN, PhD. Chairperson
Associate Professor
University of Manitoba
Position

NOTE:

Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.

APPENDIX I

INDICATORS OF THE PHASES OF INTEGRATING DIABETES

INDICATORS OF THE PHASES OF INTEGRATING DIABETES