

ADOLESCENTS WITH TYPE 1 DIABETES: AN INTERPRETIVE DESCRIPTION  
OF EXPERTISE IN EVERYDAY DECISION MAKING

by

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## ABSTRACT

### ADOLESCENTS WITH TYPE 1 DIABETES: AN INTERPRETIVE DESCRIPTION OF EXPERTISE IN EVERYDAY DECISION MAKING

Adolescence is often perceived as a challenging time and the notion of expertise in this population is not a common one. The lives of adolescents with type 1 diabetes are extraordinarily complex and their diabetes management requires them to make numerous decisions on a day to-day basis. Little is known about adolescents' everyday decision making therefore the purpose of this study was to explore how adolescents with type 1 diabetes who were nominated as having expertise in diabetes management make everyday decisions.

Using interpretive description as the methodology for this qualitative study, I employed a variety of methods to collect data from six adolescents with type 1 diabetes. I interviewed participants twice, used a "Think-Aloud" strategy that involved participants' use of an audio tape recorder to verbalize their decision-making, and I facilitated a focus group with five of the six participants in order to share my initial analysis and to generate new data. The use of a variety of data collection methods resulted in rich data that might not have been captured had I relied on a single data collection strategy.

Findings from this study revealed that participants' everyday decision making is both an art and a science, both of which are enacted in the social context of adolescents' lives. Of particular note was the importance attributed to the support of families and friends. In addition to the social context of their lives, adolescents' decision making was influenced by personal, gendered, and socio-political contexts. The contexts that emerged from the study's analysis beg for a tentative link to expertise. Although expertise in adolescents with type 1 diabetes is neither well defined nor well articulated at this time,

the findings from this study support the notion of expertise in adolescents as a credible objective. These findings should encourage us, as nurses, to try to understand and recognize expertise in adolescent clients, to acknowledge and foster it in those who have it, and to discover ways to develop it in those who do not.

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## DEDICATIONS

I dedicate this thesis, and all it represents, to three very precious individuals in my life:

My mother, Peg O'Flynn, who died, unexpectedly and many miles away, during the data collection stage of the thesis.

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## CHAPTER ONE: INTRODUCTION

The study that I describe in the first chapter of this thesis is a qualitative research project designed to explore how adolescents with expertise in their diabetes management make everyday decisions.

### **Background to the Problem**

Diabetes Mellitus is a chronic, lifelong health condition affecting 1.5 million of the Canadian population and an estimated further 750,000 Canadians have diabetes but are unaware of it (Canadian Diabetes Association [CDA], 1997; Juvenile Diabetes Foundation, 1999). The American Diabetes Association (ADA, 1999) estimates the prevalence of diabetes to be 5.9% or 15 .7 million adult Americans and, of these, it is estimated that 33% are unaware of its existence (ADA, 1999; National Institutes of Health, 1999). Over the years diabetes has been categorized according to age (juvenile-onset diabetes or adult-onset diabetes), treatment (insulin-dependent or non insulin-dependent), and/or type (type 1 diabetes or type 2 diabetes). The focus of this study is type 1, insulin-dependent, juvenile-onset diabetes<sup>1</sup>.

Although type 1 diabetes comprises a relatively small proportion of diabetes as a whole (5% to 10% of all diagnosed cases of diabetes, CDA, 1997 ; ADA, 1999 ), it is a significant one as it is usually diagnosed in childhood or preadolescence (Betschart, 1993) therefore necessitating the acquisition of lifelong management skills for diagnosed individuals. The national prevalence of type 1 and type 2 diabetes for Canada appears to be unknown. Globally, however, Canada and the United States are described as having intermediate rates for type 1 diabetes compared to high rates in Scandinavia (4%) and

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<sup>1</sup> Currently, type 1 diabetes is the most frequently used term for insulin-dependent diabetes and/or juvenile onset diabetes. Therefore, to maintain consistency, the term type 1 will be used throughout this thesis.

low rates (2%) in Japan (Health Canada, 1999). The reported prevalence of type 1 diabetes in British Columbia (BC) for individuals aged 0-19 years is 141 per 100,000 (British Columbia Ministry of Health & Ministry Responsible for Seniors, 1997). Provincially, the estimated incidence of type 1 diabetes per 100,000 children aged 0-14 years ranges from 9.3 in Montreal to 23.5 in Prince Edward Island (Onkamo, Vaananen, Karvonen & Tuomilehto, 1999). It must be noted, however, that these latter statistics are ones of incidence rather than of prevalence. Incidence refers to "new cases of a disease in a defined population, within a specified period of time" (Last, 1995, p. 82) whereas prevalence refers to "the total number of all individuals who have an attribute or illness at a particular time" (Last, p. 129). Although the incidence of type 1 diabetes appears to be increasing outside of North America it is unclear whether this trend is true in North America (Health Canada, 1999). This lack of reliable statistics can be somewhat confusing. Nevertheless, it is worth noting that type 1 diabetes is the most common endocrine disorder of childhood (Ahern & Grey, 1996; Grey, Boland, Davidson, Yu, & Tamborlane, 1999; Kyngas & Barlow, 1995;) thus rendering it an important research topic and of significant interest to nurses, especially those involved in the care of children and adolescents.

Adolescence is a process of transition from childhood to adulthood (Charron-Prochownik & Arslanian, 1997). It is a time of progressive independence and withdrawal from adults, especially parents. For adolescents with diabetes, this move toward independence may be complicated by the need for assistance from parents and health care professionals (Kyngas & Hentinen, 1995; Macdonald & Switzman, 1992; Wysocki, 1993) as they strive to achieve self-management of their chronic illness (Bennett

Johnson, 1995; Charron-Prochownik & Arslanian, 1997). It is hardly surprising that adolescence is often considered to be a challenging time in which to manage diabetes (Williams, 1999) considering the fact that parents and health care professionals must maintain a fine balance between involvement in the adolescent's diabetes management and encouragement of the adolescent's burgeoning and developmentally appropriate independence (Kyngas & Barlow, 1995).

Type 1 diabetes is a complex, lifelong, chronic health condition (Macdonald & Switzman, 1992) requiring intensive self-management skills such as self blood glucose monitoring (SBGM), frequent insulin injections, nutrition planning and regular attention to exercise (Bennett Johnson, 1995; Betschart, 1993; Grey, 2000; Kyngas & Barlow, 1995; Standiford, Turner, Allen, Drozda, & McCain, 1997; Wysocki, 1993). Adoption of these self-management skills may require permanent changes in an individual's lifestyle (Kyngas & Hentinen, 1995) and learning such skills is a challenge (Price, 1993) that is both complex (Ternulf Nyhlin, 1990) and lifelong. However, meeting this challenge is vital as failure to do so may result in acute, negative metabolic effects and the appearance of complications in the long term (Price, 1993). Prevention of these acute and chronic complications of type 1 diabetes is a major goal of diabetes management for adolescents (Betschart, 1993), thus highlighting the importance of acquiring effective self-management skills (Price, 1993).

The intensive management regimen requires the adolescent to make self-care decisions on numerous occasions throughout the day. However, it is unclear how these decisions are made as the actual decision making process has merited scant attention in the literature (Hunt Joseph, Schwartz-Barcott, & Patterson, 1992; Kelly-Powell, 1997).

Despite this, effective decision making is recognized as a crucial process that individuals with diabetes must accomplish (McLeod, 1998) in order to become expert in their own care. Gaining expertise in diabetes self-management takes time and involves the acquisition of many skills. Living with diabetes promotes experiential learning (Hernandez, 1996) which, in turn, facilitates an individual's ability to make everyday decisions that are competent, safe (Paterson & Sloan, 1994) and a good fit with the individual's lifestyle. An exploration of how adolescents with expertise make decisions about their self-care will help nurses in understanding the process so that others may be assisted in developing similar decision making expertise (Paterson & Sloan, 1994; Paterson & Thorne, 2000a).

Much of the literature pertaining to adolescent decision making focuses on high risk behavior (Beyth-Marom & Fischhoff, 1997; Frey, Gutherie, Loveland-Cherry, SooPark, & Foster, 1997; Gold & Gladstein, 1993; Hollen & Hobbie, 1996) and sexual or reproductive health issues (Brown, 1983; Keller, Duerst, & Zimmerman, 1996; Strauss & Clarke, 1992). There is minimal research addressing everyday self-care decision making. With the exception of two adult-focused studies (Paterson & Sloan, 1994; Paterson & Thorne, 2000a), no literature was located pertaining to everyday decision making in the context of a chronic illness such as diabetes and I found no research regarding this topic as it relates to the adolescent population. The paucity of research-based literature exploring the nature of everyday decision making of adolescents with type 1 diabetes has resulted in a knowledge base that is inadequate to facilitate understanding of this process. As such, it renders this study as both timely and relevant.

### **Problem Statement**

All adolescents are faced with lifestyle decisions regarding high-risk behaviors, sexual preferences, peer pressure and independence from parents. Having diabetes may make such choices more complex and individuals may be further taxed by the numerous daily decisions they must make in order to manage their diabetes. Understanding how adolescents with expertise make these decisions may assist nurses to support and acknowledge their expertise and may facilitate the acquisition of expertise in less experienced individuals. However, there is a scarcity of research-based knowledge that can help nurses understand how adolescents with type 1 diabetes make these decisions.

### **Purpose**

With this dearth of relevant literature in mind, my purpose in undertaking this study was to describe how adolescents with expertise make everyday decisions regarding their diabetes management. An increased understanding of how adolescents with expertise make everyday decisions was facilitated by an analysis of the decision making of these adolescents as articulated by the participants themselves. I was guided by Koshar (1999) who advises addressing *how* adolescents make decisions as opposed to focusing on how adolescents *should* make decisions. The findings generated from this analysis may help adolescents with type 1 diabetes who are newly diagnosed or non-expert decision-makers to develop expertise through an understanding of how individuals with expertise manage their diabetes.

### **Research Question**

My purpose in undertaking this study was to describe how adolescents with expertise in their diabetes management make everyday decisions. Therefore, the research

question guiding this study was: How do type 1 adolescents with expertise<sup>2</sup> make everyday decisions regarding their diabetes management?

### **Definition of Terms**

For the purposes of this study, major terms are defined as follows:

1. Type 1 Diabetes: "A chronic metabolic disorder resulting from autoimmune destruction of the insulin producing B-cells of the pancreas and requiring daily administration of exogenous insulin for survival" (Field & Tobias, 1997, p. 9-10).
2. Decision making: "deciding, making a reasoned judgement about something" (Hawkins, 1990, p. 208). For the purposes of this study, decision making included all decisions made by participants pertaining either directly or indirectly to their everyday diabetes management. Everyday decision making includes the frequent and regular decisions that individuals with type 1 diabetes make on a moment-by-moment, day-by-day basis. Because of the frequency of everyday decision making, individuals may not be conscious of all decisions.
3. Expertise: "expert knowledge or skill" (Hawkins, 1990, p. 280). For the purposes of this study, type 1 adolescents with expertise was understood when individuals were deemed by their health care professionals to be more skilled than most at diabetes self-care decision making. Adolescents with expertise may be defined differently by various health care professionals as indeed may be the case for self-definition of expertise. However, this study's nomination process allowed for such subjectivity, as expertise in adolescence with type 1 diabetes is, at present,

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<sup>2</sup> Individuals have diabetes - they are not diabetic. I believe this is an important distinction. Unfortunately, it is grammatically awkward to use the term adolescents with diabetes with expertise. Therefore the term type 1 adolescents with expertise is used solely for grammatical purposes.

undefined in the literature. I had hoped that allowing health care professionals flexibility in their choice of nominations might have resulted in the beginnings of an operational definition for type 1 adolescents with expertise.

### **Assumptions**

1. Adolescents who agreed to participate in the study did so willingly and honestly.
2. Adolescents can identify and reflect on their decision making processes.
3. Adolescents are capable of acquiring expertise in their own care.
4. Health care professionals can identify those individuals in their clinical practice who demonstrate high levels of expertise.
5. Expert decision making does not presume that adolescents have expertise all the time or that they make all decisions independently. It is likely that decisions are made in the context of interdependent relationships.

### **Thesis Organization**

In this first chapter, I presented the *raison d'être* of this study including its purpose, research question, definitions of terms, and assumptions. In Chapter Two, I review pertinent literature about adolescence, the impact of diabetes on this population, and decision making as it relates to adolescents with type 1 diabetes. Chapter Three's focus on methodology allowed me to present my rationale for choosing interpretative description as the methodology for this study, as well as some relevant details such as means of data collection, analytic procedures, ethical considerations, rigor, and disclosure of personal location. In Chapter Four, I describe my findings in detail. In Chapter Five, I (re) present these findings in the context of the current literature. Finally, the study is

summarized in Chapter Six, together with conclusions and implications for nursing practice, education, and research.

## CHAPTER TWO: LITERATURE REVIEW

Rather than focusing primarily on decision making in the literature, I decided to take a broader perspective in order to get an overall sense of what it is like for adolescents to live with diabetes. In a sense, this decision was made for me, as everyday decision making within the context of chronic illness is almost non-existent in the literature. Therefore, the broader focus, including a brief exploration of the adult-focused literature, allowed me to place everyday decision making within the context of adolescents lives. Furthermore, such an approach located this study within the current body of knowledge, thereby incorporating one of the basic elements of interpretive description. This approach likewise guided my data collection. I have also included, when appropriate, informal data from sources such as health care professionals known to me, individuals living with diabetes, and my experiential knowledge as a means of supplementing this review. The lives of adolescents with diabetes are unique in that type 1 diabetes requires such day-to-day attention (Brink, 1997) and such regular vigilance in order to maintain the fine balance between hypoglycemia and hyperglycemia. Its management complexity results in an extraordinarily invasive effect on the everyday lives of individuals (Faro, 1999). Not surprisingly, findings from Callaghan and William's (1994) British study, designed to explore 11 adults' perceptions of living with type 1 diabetes, revealed that the most challenging aspect of management was maintaining blood sugar levels within acceptable limits. These authors described a tension that occurs as a result of the efforts to maintain blood sugars in the normal range and possibly risking hypoglycemia, and of maintaining blood sugars higher than normal, therefore risking long term complications. Sustaining a fine balance between the two

extremes, knowing that the prevention or treatment of either one may result in the existence of the other can render diabetes one of the most challenging and intricately complex chronic illnesses to manage

### **Balance**

Paterson, Thorne, and Dewis (1998) conducted a meta-analysis of 43 qualitative interpretive research reports pertaining to adults' lived experience of diabetes and they noted that balance appeared as the dominant metaphor of the lived experience. There is no doubt that balance is indeed a common metaphor noted frequently in the literature and includes the balance between living and self-care management (Hunt, Arar, & Larne, 1998; Paterson et al., 1998). Also noted was the balance between health and illness (Ternulf Nyhlin, 1990), between emotional support and intrusion (Hernandez, Bradish, Spence Laschinger, Wilson Rodger, & Rybansky, 1997), and between hypoglycemia and hyperglycemia (Callaghan & Williams, 1994).

Although not always explicitly described in terms of balance in the literature, further issues pertaining to this metaphor in the adolescent population include balance between dependence and independence (Woodgate, 1998a), specifically between independent self-care and parental involvement (Bennett Johnson, 1995; Charron-Prochownik & Arslanian, 1997; Davidson, Boland, & Grey, 1997; Kyngas & Hentinen, 1995; MacDonald & Switzman, 1992; Wysocki, 1993), between peer activities and health choices (Burroughs, Harris, Pontious, & Santiago, 1997; Christian, D'Auria, & Fox 1999; Frey et al., 1997; Gold & Gladstein, 1993; Hern, Millar, Sommers, & Dyehouse, 1998; Kaplan & Friedman, 1994; Kyngas & Barlow, 1995; Suris, Resnick, Cassuto, & Blum, 1996; Timms & Lowes, 1999), between having a chronic illness and not being different

from peers (Davidson et al., 1997; Kaplan & Friedman, 1994; Siarkowski Amer, 1999), between disclosure and safety (Williams, 1999), between individuals' expertise and that of health care professionals, and lastly, between developmental needs and adaptation to illness (Burroughs et al., 1997; Faro, 1999).

Researchers have generally explored adolescents' chronic illness experience through quantitative methods (Woodgate, 1998a). For example, in reviewing the literature between 1967 and 1997 on children's adaptation to type 1 diabetes, Siarkowski Amer (1999) found only 1 of the 23 studies used a qualitative methodology. This quantitative approach has resulted in the use of standardized tools that were originally designed for use with children who do not have a chronic illness (Woodgate, 1998a) or for adults with diabetes (Green, Wysocki, & Reineck, 1990). These tools may not measure or be sensitive enough to capture the experience of the chronically ill adolescent (Woodgate, 1998a). Findings from Dunning's (1995) Australian study exploring 59 young adults' perspectives of type 1 diabetes revealed that 83% of participants believed that most people without diabetes do not understand what it is like to have diabetes. Although quantitative research has captured some important aspects of adolescents' experience with chronic illness, Woodgate (1998a) maintains that the use of qualitative research methods has resulted in rich descriptions of the lived experience and "findings that speak to adolescents' suffering" (p. 220).

Adolescents' experiences with chronic illness have been addressed qualitatively in a number of studies relating specifically to type 1 diabetes (Christian, D'Auria, & Fox, 1999; Kyngas & Barlow, 1995; Meldman, 1987; Williams, 1999), cystic fibrosis (Birnkrant, Hern, & Stern, 1994; Tracy, 1997) or chronic illness in general (Cappelli,

Heick, & Feldman, 1989; Woodgate, 1998a; 1998b). Kyngas and Barlow (1995) studied a group of Finnish adolescents with type 1 diabetes to discover the personal meaning that diabetes had for them. The two main categories that emerged in terms of the impact of diabetes on these adolescents were a threat to physical and psychosocial wellbeing and a healthy lifestyle or the notion that having diabetes facilitated living a healthy lifestyle. Although some participants viewed diabetes in a positive light, the majority described diabetes in negative terms such as a nightmare or a prison. A core concept to emerge from the descriptions was that of control. Similarly, in a study of young adults designed to explore the factors influencing self-management of chronic illness, Coates and Boore (1995) found that individuals needed to be in control of diabetes rather than allowing the routine of diabetes management to control their lives. Many of the Finnish adolescents in Kyngas and Barlow's study who perceived diabetes negatively felt controlled by the disease. In contrast, those attributing more positive meaning to the disease felt less controlled by it and they considered diabetes to be an integral part of their lives.

Integration has also been addressed in the adult-focused literature. For example, Hernandez (1995) developed a theory of integration based on a qualitative study of four adult women with diabetes. This author described becoming diabetic as a process involving the integration of the diabetic and personal self and including three phases: 'having diabetes', 'the turning point', and 'the science of one'. In subsequent research, Hernandez et al. (1997) facilitated focus groups with the four participants from Hernandez' original study in order to gain some comprehension of the self-awareness process; all participants were in 'the science of one phase'. These authors described self-awareness as a complicated process characterized by body listening, body knowing, body

balancing, and engaging others. This notion of integration was also addressed in the findings of Hanna, Jacobs, and Guthrie's (1995) study which explored the concept of health among adolescents with diabetes using photography as a means of communication. Having diabetes appeared to be integrated positively into participants' concept of health.

In contrast, Woodgate (1998a) identified overall negative perceptions in adolescent study participants, fifty percent of whom had diabetes while the remaining fifty percent had asthma, arthritis, Crohn's disease, or ulcerative colitis. The themes identified in this study were 'it's hard', 'it takes extra effort', 'it's restraining', 'it's painful', and 'it's a whole bunch of worries'. Similar findings were reported by Faro (1999) who assessed the impact of diabetes on overall quality of life of 23 adolescents aged between 12 - 16 years. Four major themes emerged: 1) restrictions, 2) differentness, 3) negative emotion (mainly anger), and 4) adaptation. The most predominant theme was that of the restrictions or the "I can't" message (p. 250). The future was the biggest concern for 74% of participants and many expressed their fear of developing complications such as blindness, renal disease, or limb amputations.

These findings are interesting when viewed in the light of Thorne and Paterson's (1998) meta-study of 158 research reports of chronic illness in adults. These authors identified a shift in the aspects of chronic illness that have been researched over the last 15 years. They noticed a propensity for researching the positive aspects of chronic illness whilst ignoring the more bothersome facets of such experiences. They questioned whether the shift reflects a changing perspective of individuals with chronic illness or whether it may represent researchers' agendas and priorities. Comparisons between their findings and the adolescent literature lead me to pose the following questions: Is the research on

adolescents' chronic illness experience lagging behind the adult-focused research literature? Are adolescents with diabetes less positive about the illness experience than their adult counterparts and, if so, why? Is living with diabetes more burdensome for this age group? Are adolescents more honest about the negative aspects of their experience? Are researchers unwilling to concentrate on the positive or to ignore the negative aspects of such experiences and, if so, is this dependent on participants' developmental stage or age? Although it is beyond the scope of this literature review to answer all of these questions, it may be useful to consider them as I approach data collection and analysis.

Furthermore, the actual research approach may facilitate or hinder the emergence of such positive or negative aspects of the chronic illness experience. Cappelli et al. (1989) compared participants with cystic fibrosis (CF) or diabetes to a standardized control group of healthy<sup>3</sup> adolescents. Findings from standardized scales measuring social support, coping, self-efficacy, mastery, and depression were similar for healthy and chronically ill adolescents indicating a lack of negative impact from the disease. However, the results from semistructured interviews revealed that chronically ill adolescents considered the illness to have a negative impact on their lives, especially regarding concern over their future health and the impact of the disease on their families. The discrepancy in findings between the standardized questionnaires and the interviews leads one to question the validity of measurement tools, especially for this age group, or

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<sup>3</sup> The term healthy, when used in this context, implies that individuals with diabetes are not healthy. I use this term as a representation of Capelli et al.'s usage. In no sense does it reflect my philosophy or understanding of health as it relates to individuals with or without chronic conditions. I think it is crucial to make this distinction not only because I believe that health is located within chronic illness in the same manner as it is located in those who do not have a chronic illness (Lindsey, 1996), but also because it is so easy, from a grammatical point of view, to use some terminology (as noted earlier regarding type 1 diabetes). Criticism of such usage often results in the user's rationalization that it is 'just semantics' and therefore of little consequence. I believe, in this context, that there is no 'just' about the semantics relating to one's ability or privilege to be healthy.

to hypothesize that the qualitative approach and the use of interviews may facilitate the discovery of negative feelings in this population.

In summary, diabetes is a challenging chronic illness requiring complex self-management skills and attention to many aspects of day-to-day life in order to maintain the fine balance between and among the various forces competing for attention. Overall, the majority of studies reviewed were carried out using a quantitative approach, although a number of qualitative works addressed the experience of adolescents living with diabetes. The latter approach facilitated the discovery of an overall negative theme for those adolescents living with diabetes. Based on Thorne and Paterson's (1998) meta-analysis, adults may experience fewer negative responses to living with diabetes, although their findings may have resulted from researchers' preferences for studying the positive aspects of the chronic illness experience. For the remainder of this review, I focus on developmental issues, decision making, compliance, and relationships with health care professionals as they relate to adolescents living with diabetes. I believe such a focus will enable me to place the research question within the context of adolescents' lives and to approach data collection with some understanding of the context in which adolescents with type 1 diabetes make everyday decisions.

### **Development and Chronic Illness**

In order to appreciate the impact of diabetes on adolescents, it is vital to be aware of the variety of "physical (e.g. pubertal growth, hormonal changes), psychological (e.g. newly developed cognitive abilities), emotional (e.g. mood swings) and sociological (e.g. school changes, peer pressure) demands that challenge this population" (Woodgate,

1998a, p. 210). A review of such developmental demands seems relevant given that they may significantly influence adolescents' everyday decision making.

Adolescents are neither children nor small adults (Grey & Sullivan-Bolyai, 1999; Max Quinn & Neveloff Dubler, 1997). Developmental issues facing adolescents are numerous and complex (Clark, 1998; Davidson et al., 1997; Kaplan & Friedman, 1994) and normal developmental changes proceed despite the existence of a chronic illness (Siarkowski Amer, 1999), frequently on a timeline that differs from non-chronically ill adolescents. Not only are developmental issues often more difficult for adolescents with chronic illness, they may be further complicated by illness specific stressors (Davidson et al., 1997; Deatrick, 1990; Woodgate, 1998b). Furthermore, there is a reciprocal relationship between chronic illness and adolescent development, creating the potential for further complicating the illness process or the stage of development (Kaplan & Friedman, 1994; McCormick, 1997).

Becoming independent is frequently considered the primary task of adolescence. However, adolescents with diabetes are often faced with an ambiguous need to be somewhat dependent on parents for support in achieving self-management of their condition (Kyngas & Hentinen, 1995; Macdonald & Switzman, 1992; Wysocki, 1993). As a result, adolescents may become excessively dependent on parents who may, because of their fears or overprotectiveness, foster such dependence (Burroughs et al., 1997). Nonetheless, independent self-management is achievable as long as parents and health care professionals allow adolescents an appropriate amount of responsibility for self-care whilst retaining a supportive role (Deatrick, 1990; Kyngas & Barlow, 1995). The importance of such support from family and peers has been given some attention in the

research literature, although emphasis has often been given to its relationship to metabolic control (Anderson, Wolf, Burkhart, Cornell, & Bacon, 1989; Hanson, Henggeler, Harris, Burghen, & Moore, 1989; Wysocki, 1993) rather than the emotional nurturance provided by the actual support itself (La Greca, 1992; La Greca et al., 1995).

For example, in their study of 94 intact families, Hanson et al. (1989) investigated the associations between important dimensions of family relations, including the marital satisfaction of parents, and the metabolic control of adolescents with type 1 diabetes. Good metabolic control in adolescents was significantly related to high marital satisfaction and family flexibility, although it was unclear whether poor control resulted in poor family relations or whether poor family relations led to poor control. Similarly, Seiffge-Krenke (1998) carried out a study with 89 German adolescents with type 1 diabetes, 106 ‘healthy’ adolescents, and their parents to explore changes in perceived family climate over time in families with ‘healthy’ adolescents and families with type 1 adolescents in terms of links to metabolic control. Findings revealed that ongoing parental support was necessary for good metabolic control.

La Greca et al. (1995), on the other hand, explored the type of support adolescents receive from family and friends. Findings revealed that family members provided more support for diabetes care than did friends, and friends provided more support for “feeling good about diabetes” than did family members. Findings indicated that friends were an important source of emotional support for adolescents with type 1 diabetes. Comparable findings have been reported elsewhere (Christian, D’Auria & Fox, 1999; Standiford et al., 1997). In addition, in terms of support from peers with diabetes, Meldman (1987) found that “those who did not have it wanted it and those who had it appreciated it” (p. 439).

Peers may also support adolescents as they struggle to achieve independence from parents. Such struggles may be operationalized as involvement in high-risk behaviors (Hern et al., 1998) and such involvement is often considered to be typical of this developmental stage (Kaplan & Friedman, 1994). Like adolescents without chronic health conditions, adolescents with diabetes are likely making regular, if not everyday, decisions about high-risk behaviors such as alcohol or drug use. Moreover, and perhaps not surprisingly, parents are often unaware of their adolescents' high-risk behaviors. Hern et al. (1998) carried out a study with adolescents and their parents to identify the difference, if any, between the self report of substance use by adolescents hospitalized for a traumatic injury and parents' perceptions of their adolescents' substance use. Findings indicated that parents tended to be oblivious to their adolescents' substance use as adolescents were proficient at concealing risk-taking behaviors unless they were well established habits.

Although high risk behaviors pose a threat to all adolescents, those with diabetes may be especially vulnerable (Kaplan & Friedman, 1994; Suris et al., 1996). Drug or alcohol use may be particularly complicated for adolescents with diabetes because substance use may alter glycemic control and cause other physiologic changes (Frey et al., 1997; Gold & Gladstein, 1993; Kaplan & Friedman, 1994). Despite adolescents' vulnerability, health care professionals are often uncomfortable discussing such lifestyle behaviors with their clients. For example, Schubiner and Eggly (1995) explored communication patterns between physicians and their clients using videotapes of interviews from a previous study with 30 participants aged 14 - 24 years. Findings revealed that physicians spent a lot more time discussing breast and testicular

examinations rather than high-risk behaviors such as cigarette or alcohol use. These authors speculated that physicians may be uncomfortable discussing such lifestyle issues.

Hollen and Hobbie (1996) carried out a comparative study of 52 cancer survivors aged 14 -19 years and 77 survivors' peers aged 12 - 38 years (2 were camp counselors thus accounting for the wide age range). They compared the decision making and risk behaviors of cancer surviving adolescents and their peers, and adolescent survivors reported fewer risk behaviors compared to their peers. Different findings have been reported by Gold and Gladstein (1993) who explored substance use among adolescents with diabetes (79 diabetes campers and counselors aged 11 – 25 years completed anonymous questionnaires). Twenty four per cent of participants revealed "abnormal" drinking patterns thus putting them, according to the authors, at high risk for poor metabolic control and alcoholism. In addition, an alarming 50% of 12 year olds and 40% of 16 year olds had "abnormal" scores. Furthermore, most participants described their metabolic control as good or excellent thus illustrating their lack of awareness of the links between metabolic control and lifestyle behaviors.

However, Frey et al. (1997) argue that more realistic risk perceptions are unlikely to prevent an adolescent from engaging in risky behaviors. These authors explored the relationship between perception of risk and actual engagement in risky behaviors in a sample of 155 adolescents with type 1 diabetes. Findings indicated that 62% of participants reported never engaging in any of the risky behaviors, and the remaining participants reported at least one or more than one risk behavior (18% reported one risky behavior, 14% reported 2 risky behaviors, and 7% reported 3 or more risky behaviors with alcohol use being the most often reported risky behavior). Interestingly, findings

indicated that participants perceived the risk to peers as significantly higher than the risk to self from the same risky behavior.

According to Erikson (1968), identity formation is associated with a “normative crisis” (p.17) that occurs in adolescence and young adulthood. At the same time, chronic illness may become incorporated into an individual’s identity and everyday life (Thorne, 1999), thus highlighting the potential difficulties that adolescents may face in attempting to develop an identity that is separate from their chronic illness. Williams (1999) speculated that females incorporate diabetes into their identities more easily than males. In her British study with 10 adolescents aged 15 - 18 years and a parent (usually the mother), female participants disclosed their diabetes status more willingly than did their male counterparts. Males were often unwilling to perform self-care behaviors publicly and Williams suggested that such behaviors should be seen as “a rational decision taken within the confines of the meanings of illness for masculine identities” (p. 1165). Findings also revealed that mothers of sons were more involved in their adolescents’ diabetes care than were mothers of daughters. In addition, parental expectations for self-care were higher for females than males. These findings influenced my decision to have equal numbers of female and male adolescent participants in the current study as issues of disclosure and parental expectations or assistance may play a significant role in the everyday decision-making process of adolescents with type 1 diabetes.

Kaplan and Friedman, (1994) remind us that, according to Piaget (1969), the primary cognitive task of adolescence is the progression from concrete operational thinking to formal operational thinking. Such progression has relevance for diabetes self-care, as education is usually aimed at preventing long-term complications, and the

development of formal operational thought enables adolescents to consider the potential long-term consequences of current behaviors. Although living in the present and ignoring long-term consequences are common cognitive traits of adolescent development (Hern et al., 1998), findings from some studies suggest that not all adolescents live in the present or behave without concern for the future (Faro, 1999; Kyngas & Barlow, 1995). Such findings emphasize the importance of attending to the uniqueness of individual adolescents rather than assuming that all adolescents are similar because of their development stage.

In summary, it is evident that adolescents' development is pertinent to both the chronic illness experience and the everyday decisions facing adolescents with type 1 diabetes. Adolescents face many challenges as they struggle for independence, form an identity, and develop cognitive skills. These challenges may be confounded by the presence of a chronic illness such as type 1 diabetes (Davidson et al., 1997; Deatrick, 1990; McCormick, 1997; Woodgate, 1998b). Likewise, diabetes may be complicated by the various challenges of adolescence (Kaplan & Friedman, 1994; McCormick, 1997).

Adolescents with diabetes may be further challenged by the ambivalence of needing parental assistance at a time when independence from parents is of crucial importance (Kyngas & Hentinen, 1995; Macdonald & Switzman, 1992; Wysocki, 1993). Several studies attested to the importance of support for these young individuals not only from their parents but also from their friends (Anderson et al., 1989; Christian, D'Auria, & Fox, 1999; Hanson et al., 1989; La Greca et al., 1995; Meldman, 1987; Standiford et al., 1997; Wysocki, 1993) and health care professionals (Kyngas et al., 1998).

While all adolescents may face similar challenges, those with chronic illness may be more vulnerable to the impact of some of those issues, such as involvement in high-risk behaviors (Frey et al., 1997; Gold & Gladstein, 1993; Kaplan & Friedman, 1994). Findings from studies exploring the high-risk behaviors of adolescents with type 1 diabetes revealed that they may be unaware of their increased vulnerability (Gold & Gladstein, 1993). In addition, parents may be unaware of their adolescents' substance use (Hern et al., 1998) and health care professionals may be unwilling to discuss these lifestyles issues with their adolescent clients (Schubiner & Eggly, 1995). While it is important to remember that issues such as involvement in high-risk behaviors may play a significant role in adolescent decision making, it is equally important to remind ourselves that adolescents, like their adult counterparts, make decisions within the context of their culture, individuality, and personal values (Koshar, 1999).

### **Everyday Decision Making**

*It is truly said: It does not take much strength to do things, but it requires great strength to decide what to do.*  
*(Chow Ching)*

Strauss and Clarke (1992) maintain that studying decision making during a developmental period such as adolescence presents countless challenges and these challenges may account for the sparse development of instruments to measure decision making in this age group. Furthermore, these authors question whether chronic illness accelerates or impedes mature decision making. Typical adolescent development is marked by increased responsibility for one's actions and adolescents' decision making skills may be influenced by family traits and the degree to which they have been allowed to make their own decisions and to experience the consequences of those decisions (Brown, 1983). Although adolescents have not had the same experience as adults in terms

of past decision making and problem solving (Brown, 1983; Max Quinn & Neveloff Dubler, 1997), their cognitive skills are similar (Max Quinn & Neveloff Dubler, 1997).

Development may play a significant role in the decision-making capacities of individual adolescents. For example, the development of formal operational thought enables adolescents to anticipate consequences and to weigh risks versus benefits (Kaplan & Friedman, 1994). Nonetheless, adolescent decision making is often focused on the present (Brown, 1983; Koshar, 1999) with little perception or thought of risk of future consequences (Koshar, 1999; Strauss & Clarke, 1992). Peers may significantly influence their decisions (Brown, 1983; Christian, D'Auria, & Fox, 1999; Strauss & Clarke, 1992) although parents often continue to play a pivotal role. In fact, the adolescent's self-care decision making may be significantly influenced by her or his family's support of both dependent and independent behaviors (Christian, D'Auria, & Fox, 1999). Moreover, it is crucial for adolescents to receive such support and encouragement not only from families but also from health care professionals (Christian, D'Auria, & Fox, 1999) as they learn to make decisions (Brown, 1983; Koshar, 1999).

Christian, D'Auria, and Fox's (1999) exploratory, qualitative pilot study examined the meanings of the chronic illness experience for four adolescents with diabetes in relation to taking on responsibility for their own care. All participants wanted to have more control in their lives by being more involved in decision making around their diabetes management. In addition, all participants described a turning point in their lives when they wanted to understand more about diabetes and to become more independent in diabetes management. Adults have also identified a turning point in the process of integrating diabetes into their lives (Hernandez, 1995).

Participants in Christian, D'Auria, and Fox's (1999) study began to share responsibility for diabetes care with their parents and, in the process, they gradually became more independent and self-confident in their ability to manage their self-care. The findings from this study support the view that adolescents need both knowledge and experience in applying that knowledge in order to learn to manage their self-care. Such experience included permission to make independent choices, to practice complicated decision making, and to spend time away from families in order to practice new skills. Although such independence was recognized as being crucial, adolescents also acknowledged the need for supportive assistance from family and friends (Christian, D'Auria, & Fox 1999).

Faro's (1999) pilot study assessed the impact of diabetes on overall quality of life of 23 adolescents aged between 12 and 16 years. Adolescents disclosed anxieties about managing all aspects of their diabetes regimen adequately in order to avoid complications, and those in poor glycemic control described greater worries about loss of control and hypoglycemia. These authors remind us to consider the impact such fears may have on the self-care decisions of adolescents. Furthermore, adolescents reported being most troubled by dietary restrictions including the need to follow a meal plan and the social implications of having to do so (Faro). In addition to requiring frequent daily decisions, dietary restrictions may predispose adolescents to serious eating disorders such as anorexia nervosa or bulimia nervosa (Horn & Peterson, 1997).

Similar findings regarding the impact of dietary issues have been reported by numerous authors and food concerns have been identified by both adults and adolescents with diabetes as being a major concern in everyday diabetes management (Ahern & Grey,

1996; Callaghan & Williams, 1994; Coates & Boore, 1995; Faro, 1999; Standiford et al., 1997; Weissberg-Benchell et al., 1995). The impact of strict attention to food for youth living with diabetes is exemplified by the title of a book *Sugar was my best food: Diabetes and me*, a story about the experience of living with diabetes written from an 11 year old's perspective (Peacock, Gregory, & Gregory, 1998).

Furthermore, the need to follow special diets may render individuals with diabetes as being visibly different from their peers (Okinow, 1994), a situation that adolescents are often trying to avoid. Findings from Paterson and Thorne's (2000a) adult-focused study revealed that privacy affected decisions regarding unanticipated blood glucose levels. For example, "a participant who worked in an open office was reluctant to eat at her desk because such a practice was unusual" (p. 153). Indeed, it is this 'visibility' that often distinguishes those with diabetes as being vulnerable and frequently the object of unsolicited advice or judgment regarding their food choices. Comments such as "Should you be eating that?" are not uncommon and individuals with diabetes have shared with me their discomfort and anger regarding such intrusive behavior. Not only are such behaviors intrusive, they also negate the expertise of individuals living with diabetes and assume that the 'other' knows best despite the fact that the 'other' may have a very superficial understanding of diabetes management. Further, such behaviors place individuals' private food choices in the public domain and render such choices open for discussion without the consent of the individuals making those choices. With the exception of Okinow (1994), the existence and/or impact of such behaviors was not evident in my review of the literature. Correspondingly, though attention to diet appears to have a significant impact on individuals living with diabetes, it appears to have been

given minimal attention in the literature reviewed, in that it was seldom the primary focus of research.

Clients' decision making was the focus of Bottorff et al.'s (1998) grounded theory study that explored 16 palliative care clients' experiences of making everyday choices. Most participants perceived themselves as experts in terms of their illness and their body and they valued their participation in decision making within the context of daily activities and nursing care. These authors maintain that nurses often focus on decision outcomes rather than the decision making process and, in so doing, may ignore the reasoning that precedes individuals' choices and this may encourage nurses to judge decisions as trivial or inappropriate. For example, in the context of diabetes, adolescents may try to avoid hypoglycemia by maintaining high blood glucose levels in order to avoid embarrassment in front of peers (Timms & Lowes, 1999). Should health care professionals focus on outcomes only, the reasons underlying high blood glucose levels may well be missed or ignored.

Paterson and Sloan's (1994) phenomenological study explored the everyday decision making experience of nine adults with long standing diabetes and the findings revealed that day-to-day decisions were made in the context of experience and knowledge. Knowledge was comprised of general diabetes management knowledge and specific knowledge of one's individual body responses. Deciding to assume control and assuming control were the two themes that emerged from the findings. Once individuals decided to assume control, they devised ways to maintain it, such as knowing the body, anticipating problems, developing collaborative relationships, and fostering support.

The focus of Paterson and Thorne's (2000a) grounded theory study was to determine how participants made everyday decisions in relation to unanticipated blood glucose levels (UBGLs). This study included 22 adults with long standing diabetes who were perceived by themselves or their physicians as having expertise in self-care management. Findings revealed that the process of decision making was significantly different in familiar versus unfamiliar situations. Decision making in familiar situations involved deciding what action to take, whereas the focus in unfamiliar situations was on determining the reason for the UBGL. These authors concluded that individuals with expertise use past experience to make decisions so, not surprisingly, the decision making process was considered more complicated in unfamiliar situations.

In summary, studying decision making in adolescence is a challenging endeavour which may be further complicated by the presence of a chronic illness ( Strauss & Clarke, 1992). Carnevale (1997) maintains that decision making research may be problematic in that most studies rely on self-report methods as a means of exploring decision making. Carnevale argues that such practice is grounded in the presumption that individuals are consciously aware of what they do and are therefore able to reveal how and why they do it. This author contends that such a presumption may ignore the context within which the decision is made and the unconscious components inherent in a cognitive process such as decision making. Furthermore, as noted by Bottorff et al. (1998) nurses' preoccupation with decision outcomes neglects the actual decision making process.

Several studies' findings revealed that dietary restrictions were the most bothersome daily hassle facing adolescents and adults with diabetes (Ahern & Grey, 1996; Callaghan & Williams, 1994; Coates & Boore, 1995; Faro, 1999; Standiford et al.,

1997; Weissberg-Benchell et al., 1995). Such restrictions may render individuals as being visibly different (Okinow, 1994) which can be problematic for all persons but may be especially so for adolescents.

While their cognitive development facilitates more abstract thinking, adolescents usually make decisions based on the present rather than in the context of the future implications of such decisions (Brown, 1983; Koshar, 1999; Strauss & Clarke, 1992). Adolescents continue to need support as they become more independent and learn to make self-care decisions. However, they need parents and health care professionals to be supportive without being overly protective (Christian, D'Auria, & Fox, 1999).

Although the everyday decision making of adolescents with type 1 diabetes has not been addressed in the literature, I located two adult-focused studies that are pertinent to everyday decision making and chronic illness. These studies explored everyday decision making from an adult's perspective in the context of living with type 1 diabetes (Paterson & Sloan, 1994; Paterson & Thorne, 2000a). While these two seminal studies contribute substantially to the nascent body of knowledge regarding everyday decision making in chronic illness and provided guidance for this study, it is not known whether the findings from such adult-focused studies are applicable to adolescents.

Even though everyday decision making has been given little attention in the literature, compliance is a concept that has been frequently addressed. I review some of the compliance literature because, as noted by Thorne and Paterson (2001), diabetes education is based on a compliance model even though such a model is somewhat in opposition, philosophically, to effective self-care decision making.

## Compliance

*Frustrated practitioners often express the sentiment that if patients could only see things as they did, they would naturally behave differently  
(Hunt, Arar, & Larne, 1998)*

Compliance and noncompliance, in the context of chronic illness and diabetes management, has been identified in the literature as a significant issue in adolescence (Bennett Murphy et al., 1997; Birnkrant et al., 1994; Hanna & Guthrie, 1999; Hentinen & Kyngas, 1996; Kyngas et al., 1998; Palardy et al., 1998) and may be related to issues of independence (Hentinen & Kyngas, 1996; Muscari, 1998), peer pressure, a comparatively new capacity to problem solve, and concerns regarding self-image (Muscari, 1998).

In addition, it is plausible that the results from the landmark Diabetes Control and Complications Trial [DCCT] (Diabetes Control and Complications Trial Research Group, 1994) have contributed to the continued emphasis on compliance for individuals with diabetes as this study confirmed that intensive insulin treatment resulted in improved metabolic control and fewer long term complications. However, only 195 of the 1400 DCCT participants were adolescents and current recommendations for intensive insulin treatment of individuals with diabetes may be particularly difficult for this population (DCCT Research Group, 1994; Faro, 1999; Schlotzhauer & Farnham, 1997). Reasons for this include the fact that adolescents may typically be more concerned with peer approval than with long term complications (Timms & Lowes, 1999), daily management expectations that are more arduous than ever (Faro, 1999), and the fact that such intensive management requires tremendous motivation on the part of adolescents, their families, and health care team (DCCT Research Group, 1994; Faro, 1999).

Compliance has been linked to positive relationships with families, friends, and health care professionals (Conley Wichowski & Kubsch, 1997; Hentinen & Kyngas,

1996; Kyngas et al., 1998; Lo, 1999). However, adolescence is a time when parents and health care professionals are often inclined to transfer responsibility for diabetes management from parents to the adolescent (Bennett Murphy et al., 1997; Kaplan & Friedman, 1994), a practice that may significantly contribute to noncompliance.

Hentinen and Kyngas (1996) maintain that it is the noncompliant adolescent without support who requires our attention. Health behaviors learned in adolescence may have significant consequences for individuals' health status in terms of potential complications, both short and long term (Bennett Murphy et al., 1997; Hanna & Guthrie, 1999; Palardy et al., 1998) therefore rendering the issue of compliance or noncompliance to be an important one for these young individuals with type 1 diabetes.

Moreover, compliance is often measured solely in terms of physiologic outcomes such as blood glucose measurement, specifically glycosylated hemoglobin or hemoglobin A1c (HA1c) which reflects blood glucose levels for the previous 2 or 3 months. Kuttner, Delamater, and Santiago (1990) suggest that some adolescents may comply with their diabetes regimen and have poor metabolic control, while others may not comply yet sustain good control. Health care professionals often rely solely on physiologic measures as an indication of compliance. However, a high HA1c may be caused by endogenous hormonal factors (Kuttner et al., 1990) or stress (Grey, 2000; Kuttner et al., 1990) and thus may be related to, but not caused by, noncompliance. Furthermore, there was a notable absence in the literature of issues related to below average HA1c's. Interestingly, findings from Paterson and Sloan's (1994) study revealed that participants took control of their diabetes management when health care professionals presumed, incorrectly, that the

individual had been “cheating” rather than considering other reasons for unsatisfactory blood glucose levels.

Bennett Murphy et al.’s (1997) study with 40 adolescents aged 12 - 18 years examined the role of cognitive appraisal processes in adherence behaviors among adolescents with diabetes. Findings revealed that avoidance, in the form of not checking blood sugars, was a common response when participants felt they had no control over nonoptimal blood sugars. Weissberg-Benchell et al. (1995) used the diabetes mismanagement questionnaire, a 10-item multiple-choice test to explore adolescents’ blatant mismanagement and faking behaviors. Of great interest were the reasons given for mismanagement. For example, adolescents falsified blood test results because they wanted to appear to be in good metabolic control, thus emphasizing their need to be validated for their adherence efforts regardless of their metabolic control. Perhaps such behaviors are not surprising given the fact that many health care professionals do, in fact, consider noncompliance to be the only causal factor in nonoptimal metabolic control. Hunt et al. (1998) and Hentinen and Kyngas (1996) agree that compliance measurements are problematic as these measures focus solely on outcomes rather than on process or behaviors. Hunt Joseph and Patterson (1994) found that risk-prone and risk-averse behaviours did not predict blood sugar control in adults and they speculated that it may be that knowledgeable clients know how to take sensible risks without causing negative changes in their metabolic control.

Kyngas et al.’s (1998) study of 51 youth aged 13 - 17 years explored participants’ perceptions of physicians, nurses, parents, and friends as a help or a hindrance in compliance with 26 diabetes self-care management . Findings revealed that the medical

model was still “alive and well” (p. 767) and was neither supportive of adolescents with diabetes nor facilitative of their compliance. Adolescents wanted to be treated as adults, allowed to make their own decisions, and helped to accommodate diabetes self-management into their life style. These authors suggest that what adolescents need is recognition that they are managing well in terms of both their diabetes and nondiabetes issues.

Coates and Boore (1998) agree that individuals with diabetes need decision making and empowerment skills rather than knowledge alone in order to achieve effective self-management of chronic illness. Findings from earlier work by Coates and Boore (1995) with 20 young adults aged 18 to 35 years indicated that those with chronic illness accepted responsibility for self-management and needed to integrate knowledge into their life. Further, participants required a role in making decisions about their self-care. Underlying such needs is the assumption that diabetes pervades all aspects of one’s life (Coates & Boore, 1998) and involves day-to-day, moment-to-moment issues (Callaghan & Williams, 1994).

Gallo and Knafl (1998) explored “the tricks of the trade” used by 58 families for managing childhood chronic illness. Fifty percent of the children aged 6 - 15 years had diabetes and the remaining participants had juvenile rheumatoid arthritis, asthma, renal disease, Crohn’s disease, rheumatic fever, scleroderma, or ankylosing spondylitis. The study focused on parents’ reports of 3 approaches to illness management: strict adherence, flexible adherence, and selective adherence. Although different approaches were used by participants, a basic goal common to all approaches was to control the illness and its symptoms. According to Gallo and Knafl, findings emphasized the

importance for health care professionals to recognize parents' different approaches to manage their child's illness.

Gender has been reported as a factor in compliance, with young females reporting significantly higher levels of diabetes mismanagement than young males in a study involving 107 adolescents and young adults (Hanna & Guthrie, 1999). Similar findings have been reported elsewhere related to poor metabolic control in females (Cohn., Cirillo, Wingard, Austin, & Roffers, 1997; Faro, 1999). Cohn et al. (1997) speculated that although compliance may be a factor in such differences, recognition should be given to the gender-specific biological factors that impair glucose control. One such example is the menstrual cycle. Findings from a recent British study (Williams, 1999) revealed that adolescent females were expected by their mothers to be more independent in their diabetes management than their male counterparts. Furthermore, mothers with sons were more involved in their diabetes care than were mothers with daughters. Given the importance of support to adolescents with type 1 diabetes, it is possible that such expectations and lack of assistance may have an impact on young women's metabolic control. However, regardless of the cause, it is worth noting that young women may experience poorer metabolic control than young men (Cohn et al., 1997).

Donovan and Blake (1992) maintain that noncompliance may be as widespread, if not more so, as compliance and while it may be an issue for all age groups, it is particularly common and severe in adolescence (Birnkrant et al., 1994). When noncompliance is viewed from the individual's perspective, it may be described as rational, reasoned decision making (Donovan & Blake, 1992; Thorne, 1990), often involving a conscious choice to oppose the advice of health care professionals (Thorne,

1990), and made within the contexts of individuals' beliefs and lives (Donovan & Blake, 1992). Hunt et al. (1998) contrasted the perspectives of 51 adults with type 2 diabetes and their practitioners with respect to diabetes management. Participants described themselves as never being completely compliant or noncompliant. Rather, they tended to review each behavior as a single event in the context of long term self-care. This implies that diabetes management involves many aspects such that compliance to one aspect of the regimen may be unrelated to other aspects (Glasgow, Wilson, & McCaul, 1985).

Although the term compliance is often replaced with the term adherence, Thorne (1990) maintains that such practice (merely a change in language) does not adequately address the inequalities of power that are inherent in the notion of compliance. As Coates and Boore (1998) point out "It would be unreasonable to suggest to patients that they are perceived as partners but still must do as they are told" (p. 534). Thorne (1990) agrees that compliance and independence are somewhat mutually exclusive. Coates and Boore advise a change in attitude from the notion of complying with health care professionals' orders to self-management. I believe that the concept of self-management changes the focus from a passive response to advice to a more autonomous, active behavior that is probably more acceptable, realistic, and respectful to those living with chronic illness.

In summary, while it is questionable whether compliance is relevant in the context of chronic illness, there is little doubt that it has been given, and continues to be given, much attention in the literature. In the context of diabetes, this continued emphasis on compliance may be related to the landmark DCCT study (DCCT Research Group, 1994). Such an emphasis is problematic, in part, because compliance is often measured solely in physiologic terms thus negating the contextual aspects of the situation and also ignoring

the knowledge and expertise of individuals living with diabetes (Kyngas, Kroll, & Duffy, 2000). Further, when individuals are incorrectly judged to be noncompliant they may justifiably feel resentful and frustrated. Such lack of trust may motivate individuals to take control of their own care and this may be viewed by individuals as a positive step in self-management (Paterson & Sloan, 1994) although, when viewed from the perspective of health care professionals, it may be perceived as further evidence of noncompliance.

While compliance may be a problematic concept in the context of chronic illness, it is an important one to have reviewed for this study as it appears, from the perspective of many health care professionals, to be considered a desirable component of many health care relationships and may play an interesting role in the everyday decision making of adolescents with type 1 diabetes.

### **Relationships with Health Care Professionals**

*Learning to manage self-care with a complex disease such as type 1 diabetes can be a formidable and all-consuming process. When they [individuals] perform their self-care decision making well, it may look effortless. But taking the time to understand how hard it can be, day in and day out, we [health care professionals] validate the creativity and intelligence people really do bring to their chronic illness experience. (Thorne & Paterson, 2001)*

There appears to be little doubt that the perspectives of health care professionals and individuals differ significantly in the domain of chronic illness (Hunt et al., 1998). Individuals with chronic illness are mostly concerned with fitting diabetes into their lives in experiential and social terms (Fitzgerald, Anderson, & Davis, 1995; Hunt et al., 1998; Kelly-Powell, 1997) whereas health care professionals are often focused on glucose control and view diabetes in physiologic terms (Hunt et al., 1998). For example, Warzak, Ayllon, Milan, and Delcher (1993) compared parental versus professional perceptions of obstacles to diabetes care. Only five of the ten most common obstacles rated by parents were among the ten obstacles rated by the professionals (a mixture of nurses, physicians,

dietitians, and psychologists). Conversely, some obstacles that were rated very highly by health care professionals were reported as rare and unproblematic by parents.

Thorne, Ternulf Nyhlin, and Paterson (2000) suggest that health care relationships have traditionally been based on the notion that health care professionals are the experts and the model patient is both compliant and independent. Within this relationship, the expertise of clients and families is neither acknowledged nor valued by health care professionals. Others agree that individuals' expert knowledge is often unvalued (Callery, 1997; Stacey, 1994). Yet, acknowledging such expertise is crucial to positive, collaborative relationships especially within the domain of chronic illness (Paterson & Sloan, 1994; Paterson & Thorne, 2000b) and as pivotal to living with and managing diabetes (Callaghan & Williams, 1994; Hernandez, 1995; Hunt Joseph et al., 1992; Paterson & Sloan, 1994; Thorne & Paterson, 1998; Thorne & Paterson, 2001; Williams, 1999).

Paterson and Thorne (2000b) likened the development of expertise to life's developmental stages and described it as a process involving four independent but sometimes overlapping phases; passive compliance, naive experimentation, rebellion, and active control. Findings from Paterson and Sloan's (1994) study revealed that the process of becoming expert involved making a decision to assume and maintain control over diabetes and was described by participants as growing up as a diabetic. Becoming an expert required individuals to develop a realistic perception regarding the limitations of diabetes management and an acceptance of diabetes as merely a part of one's life. Callaghan and Williams (1994) suggest that the challenge for nurses is to access this expertise and to find ways of including it in health care services. Paterson and Thorne

(2000b) agree, and suggest that such expertise may be used to promote self-care strategies among other individuals with diabetes.

Donovan and Blake (1992) maintain that the challenge for health care professionals is to understand and participate in the decisions that individuals already make. These authors suggest that the development of dynamic, participatory relationships between individuals and their health care professionals is a process that will require both individuals and health care professionals to work together, and for health care professionals to appreciate clients' decision making skills in the context of their everyday lives. Coates and Boore (1995; 1998) maintain that such relationships require that individuals be respected for the decisions that they make regardless of whether health care professionals agree with those decisions, thus rendering the notion of compliance as inappropriate for those with chronic illness. When individuals believe that health care professionals are not acknowledging their expertise or experiential knowledge and ignoring their individuality they will often avoid health care services (Callaghan & William, 1994) or ignore health care professionals' advice (Gallo & Knafl, 1998).

Hinds et al.'s (1997) study explored the decision making of parents and health care professionals when considering continued care for children and adolescent patients with cancer. Parents rated advice from health care professionals as the most important component in their decision making and health care professionals rated discussion with the family as the most important factor, suggesting that the nature of the relationship between health care professionals and clients is very important and perhaps somewhat pivotal in the context of chronic illness. Nevertheless, health care professionals may not be as influential as they might like to think they are in chronic illness management. For

example, Hernandez (1995), in a qualitative study of four adult women with diabetes, found that teaching by health care professionals was not the central factor in assisting participants to become more knowledgeable, and yet such teaching is often the principle strategy for encouraging adherence to self-care behaviors (Hunt et al., 1998). Furthermore, similar strategies are used to teach clients who adhere and those who do not (Hunt Joseph et al., 1992), emphasizing the fact that diabetes education given by health care professionals is general, assumes that 'one size fits all', and ignores the individual needs and contextual concerns of those living with chronic illness. Ternulf Nyhlin (1990) maintains that what individuals need in order to foster self-care, is information and support based on an understanding of the meaning of having diabetes.

Blum and Bearinger (1990) explored perceptions of training and competency regarding dimensions of adolescent health care via a national survey of 3066 health care professionals from five health care disciplines - nursing, medicine, social work, nutrition, and psychology. The findings were alarming in the domain of chronic illness in that 37.5% of nurses, 50% of physicians, 64% of psychologists, and 67% of social workers surveyed perceived themselves to be insufficiently trained to manage issues relating to adolescents with chronic illness.

Kyngas and Barlow (1995) found that adolescents perceived adults' expectations to be unrealistically high therefore they lied to avoid conflict. Adolescents also felt unsupported in their lifestyles and sometimes perceived both parents and health care professionals as being more interested in their disease than in them as individuals. Similar findings have been reported by Woodgate (1998b) in her exploration of adolescents' perspectives of health care professionals caring for those who have a chronic illness.

From her perspective, it is crucial for health care professionals to understand that adolescents' experience of chronic illness is not a mirror image of adults' experiences. Adolescents in Woodgate's study were very specific in their advice as to how health care professionals should care for them as adolescents with a chronic illness. "1) Treat me like a person, 2) Try to understand, 3) Don't treat me differently, 4) Give me some encouragement, 5) Don't force me, 6) Give me options, 7) Have a sense of humor, and 8) Know what you are doing" (p. 59). As always, individuals with the health condition say it best.

In summary, it appears that relationships between health care professionals and individuals are important and when those relationships are collaborative (Hernandez, 1995; Timms and Lowes, 1999) rather than paternalistic or authoritative, clients are seen as co-experts in diabetes (Hernandez et al., 1997), thus facilitating a relationship that is respectful to both parties and one that recognizes and appreciates the expertise of both (Paterson & Sloan, 1994).

However, many relationships with health care professionals are based on a compliance model in which individuals' expertise is neither acknowledged nor valued. In addition, health care professionals may have unrealistically high expectations of adolescents' ability to manage their self-care (Kyngas & Barlow, 1995) and adolescents feel that they are treated by some health care professionals as diseases rather than as individuals (Kyngas & Barlow, 1995; Woodgate, 1998b). Participants in Woodgate's (1998b) study clearly articulated how health care professionals might care for them as adolescents with a chronic illness.

## Summary of the Literature

For the purposes of this study, I reviewed the theoretical and research literature. Researchers have generally explored adolescents' chronic illness experiences through quantitative methods (Woodgate, 1998a) although some qualitative studies have been carried out to explore the lived experience of adolescents with chronic illness. Although not always explicitly stated in the literature, the metaphor of balance may describe some of the many challenges facing adolescents with diabetes. While some studies were illness specific, many were noncategorical and included a wide range of chronic illnesses. The assumption underlying such studies is that adolescents with chronic illness share similar concerns regardless of their specific illness (McCormick, 1997). There is a risk, however, that a noncategorical approach may not capture the illness specific issues that concern adolescents with diabetes on a daily basis. This was one of the reasons underlying my choice of sample for this study.

Everyday decision making has been given minimal attention in the literature. With the exception of two adult-focused studies (Paterson & Sloan, 1994; Paterson & Thorne, 2000a), I did not locate any research exploring everyday decision making in individuals with chronic illness. Paterson and Sloan (1994) maintain that this dearth of research has resulted in a lack of understanding of the practical knowledge that individuals with chronic illness accumulate as they live with their illness. Further, it is likely that such a lack of understanding may account for the invisibility and lack of value given to the knowledge of individuals with chronic illness. In addition, the everyday decision making process has not been studied, to my knowledge, in the context of adolescents with chronic illness. Therefore, I have attempted to do so in the current study.

A number of themes emerged from this review of the literature. These themes served as an organizational framework on which this chapter is based and included developmental issues, illness specific concerns, individuals' knowledge and expertise, and relationships with others. As individuals coping with a transitional lifestage, adolescents are faced with many challenges as they struggle for independence, form an identity, and develop cognitive skills. The reciprocal relationship between chronic illness and adolescent development may further complicate both developmental and illness specific issues (Davidson et al., 1997; Deatrick, 1990; Kaplan & Friedman, 1994; McCormick, 1997; Woodgate, 1998b). Despite this, adolescents' typical developmental changes proceed despite the existence of a chronic illness (Siarkowski Amer, 1999). These themes represent current knowledge about adolescents with type 1 diabetes and, as such, constitute an analytic framework that guided my data collection and analysis. Further, the framework may change should new knowledge emerge from this study.

Although it is conceivable that adolescents with diabetes have more incentive to have a healthy lifestyle or more awareness of health risks than their peers without diabetes (Frey et al., 1997), or indeed be healthier as a result of their health knowledge (Schlotzhauer & Farnham, 1997), they are also vulnerable to the challenges facing all adolescents, such as peer pressure (Frey et al., 1997), prevailing social norms (Keller et al., 1996), and social factors (Suris et al., 1996). At a time when independence from adults is desirable, supportive relationships with parents, friends, and health care professionals are crucial to adolescents with diabetes in terms of support, metabolic control, and self-care management (Anderson et al., 1989; Hanson et al., 1989; Kyngas, 1998; La Greca, 1992; La Greca et al., 1995; Wysocki, 1993).

However, not all relationships are supportive and those with health care professionals are sometimes based on a compliance model. In contrast to the dearth of everyday decision making literature, there is an abundance of literature, both theoretical and empirical, dealing with compliance. It is likely that such a model is not a good fit for those with chronic illness because compliance is often measured solely in physiologic terms (Kyngas & Barlow, 1995; Kuttner et al., 1990; Grey, 2000; Woodgate, 1998b), thus negating the contextual aspects of the situation and also ignoring the knowledge and expertise of individuals living with diabetes.

### **Conclusion**

This review has allowed me to explore what is known, to some degree, about adolescents with type 1 diabetes. This knowledge, as I understand it, constitutes an analytic framework as described by Thorne et al. (1997) as being foundational to interpretative description. The framework is based on a review and analysis of the current literature (formal knowledge) and my personal and professional knowledge (informal knowledge). As such, it guided my data collection and analysis. The analytic framework remained open to revision and was challenged by the findings from this study. The broad focus of the literature review enabled me to place the research question within the more general context of adolescents' lives. Doing so encouraged me to take a broad perspective during initial interviews with participants, and allowed me to explore and come to understand the importance of the contexts in which adolescents with type 1 diabetes live their lives.

## CHAPTER 3: METHODOLOGY

*What we think in the end is only as valid  
as the process by which we got there  
(Thorne, 1994)*

The methodology<sup>4</sup> I chose for this study is the noncategorical qualitative approach of interpretive description developed by Thorne, Reimer Kirkham, and MacDonald-Emes (1997). These authors developed this methodology as an alternative qualitative method to approaches such as phenomenology, grounded theory, and ethnography. They argue that the latter are inadequate for nursing research as they are grounded in non-nursing disciplines such as philosophy, sociology, and cultural anthropology.

Interpretive description, whilst recognizing “shared realities”, is embedded in “an interpretive orientation that acknowledges the constructed and contextual nature of much of the health-illness experience” (p. 172). The use of a qualitative research approach such as interpretive description allowed me to understand the individual perspectives of the participants in this study and enhanced my understanding of both unique and common realities, or what Sandelowski (1996) refers to as “understanding a particular in the all together” (p. 525). Therefore, this approach was an appropriate choice for my study, which explored how adolescents with type 1 diabetes make everyday decisions, with a view to understanding this process from the unique perspective of individual participants as well as appreciating the common realities of all participants.

The use of a theoretical framework to guide a study’s design may sometimes lead to an a priori view of the phenomena under study (Sandelowski, Davis & Harris, 1989).

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<sup>4</sup> My use of the term *methodology* is used to denote interpretive description, as the term implies more than simply a method. It incorporates the notion of an underlying philosophy. *Method* is used to convey ways of collecting data (Strauss & Corbin, 1998). The focus group is an example of a data collection method. Throughout this thesis, *approach* is used interchangeably with *methodology*.

Instead, in applying Thorne et al.'s (1997) interpretive description, I used an analytic framework as a guide to the study's design. In a sense, this framework represents an a priori view of the phenomena (McPherson, 1999) because a consolidation of informal and formal bodies of knowledge provided the basis for its construction. The informal knowledge that I used to build the analytic framework comprised my own personal and professional knowledge in addition to anecdotal comments from colleagues and diabetes specialists. To illustrate, prior to starting this study, I asked a pediatric clinical nurse specialist to speculate on why some adolescents are successful in their day-to-day diabetes management. She suspected that family support played a large role in adolescents' successful management. Informal knowledge such as this, in addition to formal knowledge gleaned from the literature, formed the analytic knowledge framework that guided this study. Even though, as suggested by McPherson, the use of such a framework may equate with the existence of an a priori view of the phenomena, this review of existing knowledge is crucial to the researcher's understanding of the complex nature of phenomena prior to beginning a study (Morse, 1994; Sandelowski, Davis & Harris, 1989). Moreover, the analytic framework was not 'cast in stone', as it was continually open to revision, and represented not just a single theoretical perspective but rather many perspectives gleaned from both the literature and complementary data sources.

My fundamental rationale for this choice of methodology lies in its ability to facilitate an exploration of the research question. However, an additional reason for my choice is the fact that interpretive description is a nursing method, designed by nurses to guide nursing research with the explicit purpose of developing knowledge for nursing practice (Thorne et al., 1997). The debate continues between and among nursing scholars

regarding the use of nursing knowledge versus knowledge borrowed from other disciplines. Chinn and Kramer (1999) remind us that “although theories from other disciplines are useful they do not always take into consideration significant factors that influence a nursing situation” (p. 32), and Morse (1994) claims that it is ludicrous to expect borrowed knowledge to define nursing practice. Furthermore, research that relies on theories from other disciplines may not contribute to nursing’s body of knowledge (Cody, 1994).

These concerns appear to parallel similar issues in research in that much of nursing research has been influenced, designed, and conducted using the philosophical underpinnings of other disciplines such as philosophy, sociology, and anthropology (Lowenberg, 1993; Thorne et al., 1997). To address this issue, Dreher (1994) advises the use of research methods that incorporate a holistic view of the health and illness experience within the context of nursing practice. Therefore, I began my first research endeavor by attempting to tip the balance in nursing’s favor by using a methodology that aligns itself with nursing philosophy and, in so doing, I believe I conducted research that is specifically designed for and applicable to the practice of nursing. Furthermore, by using such an approach I began “the process of legitimizing it within our scholarly discourse” (Thorne et al., p. 172).

### **Participant Selection**

Thorne et al. (1997) advise the use of purposeful sampling, wherein initial participants are selected on the basis of their ability to contribute to the knowledge under investigation (Morse, 1991; 1999a). However, subsequent participant selection may depend on ideas that evolve during the research process, a strategy known as theoretical sampling (Sandelowski, Davis & Harris, 1989). Predicting the sample size depends on a

variety of factors (Morse, 2000). Generally, however, a reasonable sample size is small enough to obtain rich descriptive analysis and large enough to facilitate an understanding of individual participants' experiences (Sandelowski, 1995a). Consequently, although I anticipated six participants to be an adequate number, depending on the information obtained and adolescents' willingness to participate, I recognized that the sample size might be smaller or larger than predicted. However, the final sample size did indeed match the predicted number of six.

To facilitate purposeful sampling, health care professionals at a major tertiary care pediatric facility in western Canada were asked to nominate adolescents with expertise for this study. In addition, two adolescents were nominated by health care professionals who knew them personally, but were not their professional caregivers. One nominator was not a diabetes specialist. A letter describing the study was sent to nurses, physicians, dieticians, and social workers involved with adolescents with type 1 diabetes, requesting their participation in the nomination process. Within a few weeks I contacted health care professionals asking for names and telephone numbers of interested nominated individuals whom I then contacted to provide a detailed explanation of the study and to invite their participation. At that time, I explained and reinforced the notion of anonymity and confidentiality, reassured listeners that there was no obligation on their part to agree to participate, and that there would be no negative consequences should they refuse to participate in the study or to withdraw from the study at a later time. When an individual agreed to participate I arranged a mutually convenient time in which to conduct the initial interview at a location of her or his choice. At the end of the initial interview we discussed a timeline for the Think-Aloud method of data collection (see Appendix H) and a second

interview. This nomination process has been used successfully in a similar adult-focused study (Paterson & Thorne, 2000a) and this work provided me with a guide for the design of the nomination process and data collection.

### **Recruitment Process**

The recruitment process was quite a lengthy one and I suspect that the nomination style of recruitment contributed to the delay in the following ways:

- 1) Many of the health care professionals at a major tertiary care pediatric hospital in western Canada were unable to participate as their clinical practice involves adolescents who did not meet the criteria for expertise in diabetes care. For example, the social worker claimed to see only the ‘problematic kids’ and the clinical nurse specialist (CNS) sees mainly the newly diagnosed adolescents.
- 2) One of my greatest resources for nominations, the clinic nurse, was on an extended leave over the summer months and was, therefore, unavailable to nominate clients. It was apparent, from the health care professional’s perspective, that the process of nomination required a relationship with the potential nominee and an expertise on the part of the health care professional to recognize expertise in clients.
- 3) I had anticipated that the summer would be an appropriate time to collect data, but I discovered that many of the adolescents seen at the pediatric hospital over the summer are from out of town. This policy is in effect to facilitate clinic appointment access during the holidays for those living far away. Consequently, many of the summer “visitors” were ineligible for my study.

I found the nomination process to be a little problematic in that the nominations given by professional caregivers and diabetes specialists differed considerably from the nomination put forth by a health care professional who was neither a professional

caregiver of the nominee nor a diabetes specialist. That is not to say that professional caregiver nominations were unproblematic. There were limitations to the nomination process, criteria were flexible, and expertise was very loosely defined. I made these decisions, in part, because expertise, in this context, has not been well defined in the literature and the loose definition allowed for the possibility of furthering my understanding of what this concept represents, not only to others in the field, but also to the participants themselves. The issues I encountered with the nomination process will be discussed in Chapter Five.

### **Data Collection**

Data collection consisted of two individual, tape-recorded interviews, tape recordings by participants of their daily decisions regarding diabetes management for a one-week period at some time in between the two individual interviews (the “Think Aloud” technique), and a final focus group interview with other adolescents who had participated in the research, during which time I also shared my findings and explored participants’ reactions to these findings (Paterson & Thorne, 2000a).

The initial interview facilitated my use of open-ended questions, allowed me to gather demographic data (see Appendix G), and provided a forum for individual participants to share their experiences. I had planned that the second interview would, ideally, have been conducted within two weeks of the Think-Aloud process but this was seldom the case due to time constraints and schedule conflicts. Second interviews were guided, in part, by the data generated from the initial interview and the Think-Aloud process. The analytic framework guided all data collection. The final group interview or focus group allowed me to share my findings with participants, to elicit their response to these findings, and to generate further data.

All initial interviews were face-to-face and, when I visited several homes, I noticed an almost tangible sense of familial support for participants. A busy family life and interest in the study were obvious in four of the five interviews conducted in participants' homes. In addition, during the initial telephone contact, several mothers spoke enthusiastically about their adolescents' self-care. All interviews lasted approximately one hour each and were transcribed verbatim as soon as possible after the interview either by myself or by a professional typist. Five adolescents chose to participate in their second interviews over the telephone. The sixth participant requested that we conduct the second interview in person and I was happy to accommodate his request. Some Think-Aloud entries were completed traditionally and others more creatively. For example, two of the participants found the Think-Aloud process to be rather problematic in that they were unmotivated and needed some structure so we agreed that I would telephone them nightly for a one-week period. Basically, this resulted in several mini interviews that were labor intensive but resulted in rich data.

The Think-Aloud process is a research method intended to generate knowledge about participants' thinking and decision making by having them verbally express their thoughts or cognitive processes (Bakken Henry, Belongia LeBreck, & Holzemer, 1989; Fonteyn & Fisher, 1995). Fonteyn and Fisher attribute the origins of the Think-Aloud method to the work of Ericsson and Simon (1993, as cited in Fonteyn & Fisher). Fonteyn and Fisher used this method successfully to explore nurses' reasoning and decision making about actual rather than simulated patient care. With the exception of Paterson and Thorne (2000a) and Paterson, Thorne, Crawford, and Tarko's (1999) work in chronic illness, this technique has not been widely used with clients as a means of accessing their actual decision making process in the context of everyday life. Participants were supplied

with tape recorders and advised to "talk their thoughts" about their everyday diabetes decision making into the tape recorder for a one week period. Participants were given specific written guidelines in addition to a verbal explanation of the Think Aloud method (See Appendix H). Four Think-Aloud entries were completed traditionally, but did not always result in the rich data that I expected. Some were rather clipped accounts of foods eaten throughout the day. What was sometimes interesting, however, were the discrepancies between what participants reflected on in the first interview and their actual decision making as described in the Think-Aloud process.

Focus groups are an efficient means of generating data from a number of participants (Reed & Roskell Payton, 1997) and the generated data are quite different from those obtained via individual interviews (Morse & Field, 1995). This may be due, in part, to the interactive process that enables the researcher to use everyday group communication styles or strategies such as the use of humor or teasing (Robinson, 1999); such strategies may be inappropriate in the individual interview. I enlisted the help of a colleague for the focus group, as the use of two researchers is recommended so that the facilitator is free from the role of note taking and monitoring the tape recorder (McDaniel & Bach, 1994; Robinson, 1999; Sim, 1998).

I conducted the final focus group in the hospital setting on a sunny Sunday afternoon. Five of the six participants attended and I received permission to send the focus group tape to the sixth participant for review. The main objective of the focus group was to share my interpretations of participants' stories and to ask for validation or refutation of these interpretations. In addition, I anticipated that some new data might emerge. Interestingly, some of the stories told at the focus group were 'confessional' in nature. The process of using a variety of data collection strategies may well be crucial for this

population if the findings from this small-sample study reflect adolescents' ways of sharing potentially sensitive information. I discuss the implications of such findings in Chapter Five.

### **Data Analysis**

Data analysis was inductive rather than deductive (Thorne et al., 1997). Hence, to a large degree, analysis relied on the nature of the findings (Dreher, 1994), thereby giving data a dominant role within the study (Morse, 1999b). The process of data analysis includes data management strategies and cognitive analysis tasks. The former facilitate the latter and it is worthwhile to develop an effective means of managing data so that they are organized and easily retrievable (Morse & Field, 1995). These processes occur concurrently and data management often generates analysis and visa versa (Sandelowski, 1995b). Knafl and Webster (1988) explain that "data management tasks are...typically reductionistic, because they convert the data to smaller, more manageable units that are easily retrievable" (p. 196). Initially, as a way of managing data, I diagramed some of my ideas on a large construction board as I found this strategy to be a helpful tool in visualizing and reducing what were often voluminous amounts of information. These initial themes were not specific to decision making as they were based on preliminary interviews; interviews that allowed and encouraged participants to speak broadly about their lives as adolescents with type 1 diabetes. Trying to understand the broad context of adolescents' lives was crucial to my thinking before attempting to move forward in an exploration of their decision making. In addition, I jotted down some powerful quotes without attending to themes. At this stage, I found the quotes brought the participants alive in the midst of voluminous data.

Subsequently, I began to conceptualize themes without giving much thought to actual quotes. I focused on the overall research question of how adolescents with expertise with type 1 diabetes make everyday decisions by asking the following two questions of the data: What does this decision making depend on and what does it involve? Although tempted, I avoided reference to the literature at this point to ensure that my analysis of the findings were unique to this study rather than a rewording of themes found in similar work by other authors. My approach was based on the underlying principles of Thorne et al.'s (1997) interpretive description that assume the use of inductive analysis, the avoidance of premature and overly complex coding systems, and the use of general questions such as "what is happening here?"(p. 174).

Cognitive analysis tasks, as opposed to those of data management, "facilitate extracting the meaning from a data set and are constructionistic because they focus on rebuilding and presenting the processed data in a thematic or conceptually relevant whole" (Knafl & Webster, p. 196). To this end, I was guided by Morse (1994) who maintains that four cognitive processes are integral to all qualitative analysis. These are comprehending (understanding), synthesizing (integrating), theorizing (proposing, linking to existing theory and making links among the data), and recontextualizing (abstracting the findings). My objective was to locate my findings within the context of current knowledge and to distinguish between findings that support that knowledge versus findings that are new contributions (Morse).

To begin, I compared the transcript of each interview with the original audiotape to ensure accuracy and to immerse myself not only in the data but also in the many nuances that are evident in the interview: the voice and intonations of the participant and myself:

nuances that are often lost when transcribed to paper. From the outset, I immersed myself in individual transcripts from original interviews. This allowed me to begin to understand individual experiences (Sandelowski, 1995b; 1996; Thorne et al., 1997) prior to using a similar process with other initial transcripts and with subsequent transcripts from the Think-Aloud audiotapes and second interviews. This immersion facilitated a preliminary understanding of each interview in its entirety and was followed by a similar process with the other transcripts. This repetitive immersion is advised by Thorne et al. (1997) before attempting to discern patterns, themes, similarities, and differences among participants' experiences.

In the final report, having derived my findings from the data (Sandelowski, 1986), I describe and interpret those findings in terms of abstractions or theoretical themes. Furthermore, my interpretations are contextualized so that there is evidence of individual differences as well as commonalities (Thorne et al., 1997). To this end, direct quotes from original transcripts are used to illustrate participants' experiences without breaching the principles of confidentiality and anonymity. I anticipated that this study's predominant significance would be for nursing practice. Nevertheless, I believe that there may also be some findings that are theoretically significant in terms of adding to the current knowledge base regarding everyday decision-making expertise in adolescents with chronic illness.

### **Ethical Considerations**

Permission for this study was sought from the Behavioral Research Ethics Board at the University of British Columbia and the Ethics Committee at the hospital where the participants received care. Informed consent was an especially important issue for adolescent participants as parents were also required to give consent, thus potentially undermining the adolescent's autonomy. For this reason, I designed individual consent

forms for both participants and their parents as opposed to requesting adolescent assent and parental consent, a common strategy used when researching young clients.

Adolescents were informed that parents would not be attending interviews and assured that they could refuse to participate, decline to answer specific questions or topics, or withdraw from the study at any time without jeopardizing their health care.

Participants chose or were assigned pseudonyms to maintain confidentiality and anonymity and their identities are known solely to me. Direct quotes were not always joined to specific pseudonyms (Morse, 1998). There will be no risk of identifying participants should this research lead to publication in either professional or lay journals.

Participant's contact data was stored separately from the remaining research materials.

The researcher stored all tapes, transcripts, discs, or other materials securely. As a means of facilitating potential secondary analysis, raw data will be kept for a period of five years following completion of the study and then destroyed. Raw data, including audiotapes, transcripts, and computer discs, contain no information linking them to participants' identities.

As well as considering issues of consent, ethical approval, confidentiality and anonymity, I gave some thought to the notion of treating valuable human resources such as personnel and study participants in an ethical manner. By this I mean to imply that my choice of the study will or should have significant implications, however small, for nursing practice and ultimately for those individuals for whom we provide care. To this end, I believe it is crucial, following completion of this study, to disseminate the results not only to professional colleagues but also to individuals living with diabetes. In addition, I was guided by Gregory, Russell, and Philips (1997) who remind us of the importance of valuing transcribers as persons, urge us to acknowledge their vulnerability, and advise the

use of specific strategies to minimize the risks of such vulnerability. Such strategies, as identified by these authors, include fully informing the transcriber about the character of the research, implementing periodic debriefing meetings between researcher and transcriber, and warning the transcriber about potentially challenging interviews.

There were no known risks to this study. The main benefit to participants was the chance to enhance nursing knowledge and potentially to assist other less experienced individuals with type 1 diabetes. Also, it may have been advantageous to express feelings about having diabetes and to have been acknowledged by health care professionals or parents as having expertise in their self-care management.

### **Location of Self**

*If you do not tell the truth about yourself  
You cannot tell it about other people  
Virginia Wolfe (1882 - 1941)*

I am the parent of two children, one of whom has type 1 diabetes. My daughter, aged 13 years, developed diabetes as a toddler. Consequently, we have lived with diabetes for a decade. From the outset of this research I recognized a reluctance to publicly disclose my personal location. The notion of doing so with potential research participants presented me with no dilemma providing I had given the issue some thought and had reached the conclusion that it would be in the best interests of both the participants and the research process. My reluctance had more to do with disclosing my location and committing it to paper with the understanding that readers' interpretations of my work would subsequently be viewed in the context of that disclosure

I suspect that my uneasiness stemmed, in part, from my belief that many health care professionals align with the positivist view of researcher objectivity (an unrealistic expectation in terms of merging personal experience with a substantively similar professional role) and perhaps consider the physician or health care provider as the one

and only expert, thus potentially rendering my experiential knowledge as somewhat invalid or undervalued. If, however, I aspire to a non-alignment with the positivist paradigm in terms of knowledge and research then I must strive to do likewise within the context of disclosing my personal location. As a result of my desire to care for people with chronic illnesses professionally, I have, since beginning my Masters program, undertaken both practical and theoretical reflective work as a means of discovering if a merging of the two roles was a feasible option. This reflective work has, I believe, helped me to acknowledge my personal location. Further, it will provide a foundation for ongoing reflection throughout the research process.

Living with and caring for a child with a chronic illness has been an insightful experience. It has taught me a great deal about the complexities of the chronic condition itself, the expectations of oneself and others in the light of being a health care professional and a parent, but perhaps most importantly, in the context of this research, it has given me an unequivocal understanding of and respect for the expertise of individuals who are living with a chronic illness.

So, I challenge you, the reader, to consider your interpretation of this work in the context of your personal and professional assumptions or biases regarding personal disclosure issues such as mine and, in so doing, I urge you to consider the perspective of Sword (1999) who maintains that “locating oneself in the research endeavor does not lessen the credibility of its product as a representation of the experiences of others. Rather, it makes explicit how our stories are context bound and strengthens one’s integrity as a researcher” (p. 277).

### **Interesting Dilemmas**

I began the focus group by sharing my personal location with participants (i.e., I am a parent of a child with diabetes). I had not done so at the beginning of the study because I suspected that adolescents might then view me predominately as a parent. When I asked the participants if sharing my personal location at the beginning of the study would have made a difference, three of the five participants admitted that they would not have given me the same data had they known my personal location. In one sense, their responses validated my decision; in another, it made me question the ethics of not having told them at the outset. However, they reassured me that they did not mind that I had not shared this information earlier.

Throughout the research process, I grappled with my part in it all. Not only did I choose not to disclose my personal location until the final focus group, I frequently wrestled with being a nurse versus being a researcher. How was I, as a nurse, shaping the process by the questions I asked, the direction in which I steered participants, and the issues I returned to in subsequent interviews? These are issues that are potentially problematic for many researchers and I reflected on and discussed them with colleagues and members of my committee in order to put such concerns in perspective. Consequently, there were occasions when, from an ethical perspective and with participants' safety in mind, I donned my nurse's hat and tried to dispel some misinformation that participants held.

### **Rigor**

Rigor, a term that Sandelowski (1993) maintains is too harsh, encompasses the integrity of a study, and attention to rigor is a crucial aspect of maintaining that integrity within interpretive description (Thorne et al., 1997). Lincoln and Guba (1985) claim that

the four aspects necessary to ensure the trustworthiness of qualitative research are truth value, applicability, consistency, and neutrality. To address these issues of rigor, I did the following:

My findings and analysis were grounded in the data, ensuring that findings “fit the data from which they are derived” (Sandelowski, 1986, p. 32). I verified my findings and my initial analysis of those findings with participants (Sandelowski 1993; Streubert & Carpenter, 1994) and I communicated periodically with my thesis committee as a means of corroborating or disputing my analysis.

I intended to keep written notes throughout the research process to enable others to verify my decisions, thoughts, insights, and ideas (Morse & Field, 1995) thereby leaving a clear decision trail for others to follow (Sandelowski, 1986). However, I discovered that this was rather challenging to do as my thought processes sometimes moved and changed at an alarming rate. Nevertheless, I have attempted to describe my thought processes, albeit briefly, in the data analysis section.

I maintained a reflective perspective as a means of pondering the effect the researched and the researcher may have on each other; a process known as reactivity (Paterson, 1994). I acknowledge that I have many biases and beliefs: personal and professional, conscious and unconscious. Acknowledging one’s biases, however, does not automatically ensure an ability to put such biases aside. Therefore, my reflective stance allowed me to explore the influences such biases may have on data collection, management, and analysis. I explicitly describe such influences, when they occurred, in my final report to enable readers to see how such biases feature in the overall research process. Although the acknowledgment of one’s biases does not ensure an ability to put such biases aside, I tried to do so in order to minimize their influence on the research

process. Putting aside such biases represents one's reflective skills rather than one's objectivity (Ahern, 1999), and so self-reflection and discussion with committee members allowed me to contemplate both reactivity and biases. It is my belief that it is impossible and not necessarily desirable to remove all subjectivity from work such as this study therefore I concede that it was biased to the extent that it was carried out, managed, analyzed, and interpreted through the lens of a particular individual - myself.

### **Limitations**

Although this study was carried out under the supervision of an experienced group of nurse researchers, the interviews were conducted by a neophyte investigator. My inexperience may have resulted in a less than optimal interview technique as well as a difficulty in obtaining the richest data possible. A second limitation involves the sampling criteria, which demanded that participants were fluent in English. This strategy may have excluded non-English speaking and limited English proficient participants with expertise. Third, the nomination style of sampling assumed that the health care professional is the best judge of the expert decision-maker, whereas parents may be equally or better able to judge the expert decision-making skills of their adolescents. Furthermore, adolescents themselves may be the most appropriate judges of their own expertise. Finally, the lack of a clearly articulated definition of expertise was challenging.

### **Summary**

In this chapter, I provided a description of, and my rationale for, using interpretive description as the methodology for this study. In addition, I addressed the ethical implications of conducting such research, the importance of attending to the study's rigor, and my personal location in the context of this work.

## CHAPTER FOUR: THE ART AND SCIENCE OF EVERYDAY DECISION MAKING

*"The little girl had the makings of a poet in her who,  
 being told to be sure of her meaning before she spoke, said:  
 'How can I know what I think till I see what I say'?"  
 (The Art of Thought, Graham Wallas, 1858-1932)*

In this chapter, often referred to as the “findings” chapter, I share participants’ accounts of how they make everyday decisions with the understanding that these accounts have been and are (re)presented and interpreted through my individual, subjective lens. In addition, I share some of the issues I encountered during the research process, how I resolved them, and my thinking processes in relation to these decisions, in an effort to clarify my reasoning for the directions I took and the final interpretations I made.

### Description of Participants

In all, there were six participants, three female and three male, ranging in age from 14 to 18 years. All the participants are Caucasian, and have lived with diabetes for 3 – 9 years. “Alyssa,” “Hayley,” “Ivan”, “Roger,” “Sam,” and “Samantha” live in the lower mainland and speak English fluently. I obtained informed consent from participants and a parent, always the mother. With one exception, all are high school students, live with both parents and siblings, and attend a pediatric health care facility where care is given by a team of diabetes specialists including a nurse, a dietitian, and a physician.

### Overall Interpretations

*"My experience with diabetes has been positive  
 but it's not something that is positive."(Sam)*

Many participants reflected back on the early days following diagnosis and spoke, not too fondly, of rigid schedules, weighing and measuring food, and a lifestyle that was dominated by the diagnosis. In contrast, the expertise they gained from having lived with type 1 diabetes for a few years gave them a flexibility that they treasured, allowed them

to efficiently manage their diabetes, make effective self-care management decisions, and helped to ensure that diabetes was not always at the foreground of their lives.

For the most part, adolescents took their self-care decision making quite seriously but there were limits to what they were prepared to do on a daily basis and the extent to which they were willing to allow diabetes and its management to invade their lives. Decision making was seen as a part of the context of everyday life and required adolescents to practice what I call the art and science of everyday decision making. Therefore, the interpretations I have constructed from the data will be discussed within three major themes of adolescent diabetes management: the art; the science; and the art and science in a social context.

The art and science of decision making in a social context illustrates the context in which adolescents make everyday decisions and provides insight into how others play a part in such decision making. In the following pages, I present my interpretations of the findings as abstractions or theoretical themes and, in so doing, reveal patterns that I noted in participants' experiences. Furthermore, I use direct quotes from original transcripts in order to contextualize these themes, to demonstrate the origin of my interpretations, and to illustrate both the similarities and differences in participants' experiences.

Some of my interpretations changed throughout the analytical process. For example, initially, I believed that art and science were somewhat paradoxical but, as I immersed myself in the data, I came to understand that they were, for the most part, complementary rather than contradictory. In fact, at times, it was quite challenging to separate them totally from one another and to fit themes into discrete categories. Nevertheless, I developed the three themes described in this chapter with the understanding that the boundaries were somewhat artificially constructed for the purpose

of the analysis, and with a view to presenting a clear and coherent interpretation of the findings from the study.

Throughout my analysis of the data, I noted paradoxes in addition to the one mentioned above. For example, participants described what they do everyday as nothing special although they also recognized that it was what they do everyday that constituted their expertise and justified their inclusion in this study. One participant confirmed this, saying,

I was just surprised cause I didn't think I was doing anything special. I was just doing what I've learned to do I guess. I guess I'm kind of an expertise [sic] cause I've been doing it – it seems like forever but I wouldn't think that I was anything special or anything.

Diabetes, for the most part, was an element of everyday living and adolescents positioned diabetes in their daily lives as something routine that had to be managed in order to get on with the important aspects of living. Adolescents appeared to minimize the impact of the chronic illness in order to live their lives as adolescents despite having a chronic illness. One participant explained,

It's not that big of a difference – like there is a difference but when I first went to the hospital – when I was first diagnosed with it they made it seem like it was – like it is –like something – like a big deal but it almost made it seem it's a real different life than I think but you just have to watch what you eat and like exercise and stay healthy and make good decisions and stuff – be careful. But I don't think it's like someone had to go 'Oh, I feel sorry for that person' – you know what I mean – it's not like a big deal or anything.

Sam explained that diabetes did not have a large impact on his life, yet he then went on to describe how diabetes impinges on numerous aspects of his day-to-day life and decision making. Other participants also described diabetes in terms of being "not a big deal" although their stories involved descriptions of incredibly complex decision making. Such complexity was taken in their stride and participants' stories may reflect the blasé attitude of experienced individuals who have incorporated intricate self-care

management into their daily lives. Participants attended to the responsibilities of everyday self-care and viewed available resources such as glucometers as useful tools to help them manage everyday diabetes-related tasks so that they could then get on with everyday living.

In contrast, Roger believed that the best way to live his life was to ignore the diagnosis as much as possible. He did understand and articulate the necessity of insulin but felt controlled by a disease that made him different and required his body to be dependent on a drug. Roger perceived blood sugar checking as a mechanism that forced him to acknowledge his diabetes, render it visible, and ultimately made him feel that diabetes controlled him.

### "Roger"

From the outset, I grappled with Roger's data and how he fit in to the study. Because I was interested in exploring adolescents with expertise in diabetic management, I struggled with the notion that he did not, in my view, have this expertise. Some of my committee members and research colleagues recommended that I exclude him from the study, but I was resistant to that plan even though I understood the rationale behind it. Roger was similar to other participants in that he listened to low blood sugar body signals and based some of his decisions on convenience although the type of decisions he made were quite different from those of other participants. Despite some similarities, the differences between Roger's data and that of other participants were monumental and include his:

1. conceptualization of himself as being unable to be healthy,
2. negative view of diabetes,

3. response to scientific guidelines (for example, he seldom checked blood sugars, ate whatever he wanted and based food choices on wants, needs, and boredom rather than recommended guidelines or diabetes choices, lived a very inactive lifestyle, and his decisions were often based on ignoring and denying diabetes),
4. recognition that he did not practice what he knew to be competent self-care,
5. perception of family support as nagging,
6. placement of diabetes in the background by ignoring it as opposed to attending to the necessary aspects of diabetes and then placing it in the background.

Based on these interpretations, I wrestled with Roger's inclusion for the following reasons: First, would Roger and others (i.e., the primary parent or health care professional, neither of whom had nominated him) believe him to have expertise simply because of his inclusion in my study? I was able to address this question in the second interview that I had with Roger. When asked if he or significant others (primary parent or physician) considered him to have expertise, he believed that neither his parent nor physician would have nominated him for the study. In addition, as we explored this issue, Roger conceptualized expertise in two ways: expertise in knowing and expertise in doing. He believed he had the former but not the latter.

Second, would the inclusion of an adolescent without expertise compromise the integrity of the study? I asked myself what was the most important -- Including all participants' perspectives or maintaining the integrity of the study? Although I decided that maintaining the integrity of the study was my top priority, I recognized that they were not mutually exclusive and that retaining Roger's perspectives would be very useful in challenging my thinking and strengthening the study's findings through a process of comparing and contrasting my interpretations of his experiences with those of other

participants. In so doing, I believe that Roger's inclusion not only maintained the study's integrity but actually enhanced it.

Specifically, Roger's conceptualization of expertise forced me to reflect on my own assumptions about expertise. Until that point, I had thought about it more in terms of doing rather than knowing, with the underlying expectation that expert doers have expert knowledge. Roger's understanding of expertise challenged not just my own thinking but also encouraged me to ask other participants how they conceptualized expertise. Participants agreed that expertise could quite justifiably be conceptualized as knowing or doing. Alyssa likened it to peoples' smoking knowledge and behaviors, saying, "Yeah, I do agree. Like, it's something like, I guess you could explain it, like people say like 'don't smoke, it's bad for you' but people do it anyway."

Indeed, adolescents sometimes made choices that were incongruent with their expert knowledge. However, these choices, in contrast to Roger's choices, were occasional rather than habitual. So, while there are few of Roger's direct quotes in the text, he was a powerful presence underlying many of my interpretations, particularly in the realm of expertise.

As I thought about how these concepts fit into the main discourses shared by adolescents I came to understand that, although there are overlapping elements between domains, the knowing underlying decision making paralleled the science and the doing was associated with the art of managing life as an adolescent with diabetes.

#### The Cart Before the Horse: Science Precedes Art?

Can the art or the science stand alone? I suspect that you can have the science without the art and often do, particularly in the early days following diagnosis, but you cannot have the art without the science (at least in the context of expertise). Science is a

prerequisite for the acquisition of art. Science represents both the basic and complex knowledge that is necessary in order to master the art of everyday decision making.

Without a grounding in science it would be virtually impossible to acquire an expertise that is congruent with the art of self-care expertise. Adolescents' stories describing the rigidity or tight management structure necessary in the early days parallels the notion of the science underlying decision making, whereas the art is exemplified by the relative flexibility that they had come to know and treasure.

Participants' stories imply that scientific knowledge is at the foreground of decision making as individuals and their families begin the process of managing diabetes care. Over time, as adolescents lived with diabetes, their scientific knowledge shifted to the background and became a foundation on which to base their decision making.

Adolescents did not always listen to science. Sometimes, they chose to ignore it but, for the most part, this was occasional rather than frequent. The science of decision making is somewhat acontextual and general and is, therefore, of crucial but limited value. Roger, for example, believed himself to have scientific knowledge in that he knew what he "should" do but he did not do it. Also, he appeared unable to customize for himself the scientific principles of diabetes management. In my view, artfully applying the general and acontextual knowledge to living life with diabetes constitutes expertise and it is this expertise that constitutes the art of decision making.

While it is within science that knowledge and cognition fit, there is little doubt that there are elements of both within the art domain. It is in the application of scientific knowledge that the art of decision making becomes evident. Artfully applying the general scientific principles of diabetes management to the unique requirements of everyday self-care is the foundation of expertise and personifies the uniqueness of each individual's

experience. The science of everyday decision making speaks to generalities whereas the art encompasses the individuality and uniqueness of different individuals living the same (in general terms) yet uniquely different experience. Such an interpretation fits well with interpretive description in that a focus was given to both the unique and the similar, privileging neither while acknowledging both. I posit that living “well” with diabetes is an art in and of itself. The how of living well with diabetes constitutes naming it as an art. The very word implies an ease and an effortlessness but this is not always the case, as Sam explained, “It’s like an art – you have to keep it [blood sugar] between those two things but sometimes you’re not able to – you try it and try it but you just can’t.”

Overall, participants’ decisions were based on knowledge of diabetes in general (scientific knowledge) and/or knowledge acquired from living with diabetes (somewhat scientific but also incorporating the art), while taking into account individuals’ uniqueness (the art) and the social context of adolescents’ lives. It is this art and science of everyday decision making within the social context of adolescents’ lives that frame the interpretations described in this chapter.

### **The Science**

As I understand it, for the participants in this study, the science underlying everyday decision making encompassed the basic prerequisite knowledge that was crucial to adolescents and their families as they began to live life with diabetes. A diagnosis of diabetes required that adolescents learn the scientific principles of diabetes and its management. Subsequently, participants used those scientific principles to consider the future implications of having diabetes and to develop guidelines for everyday decision making. Finally, adolescents used not only scientific principles but also scientific innovations to enhance and fine-tune the numerous decisions they made on a daily basis.

### Gaining Scientific Knowledge

One of the ways that participants attended to scientific principles was through the use of scientific knowledge. Ongoing clinic visits provided opportunities for health care professionals to advise adolescents about ways of managing diabetes and presumably this advice was based on scientific knowledge. However, the knowledge acquired at the time of diagnosis appeared to constitute the bulk of scientific knowledge that adolescents used in making decisions in their everyday management. Initially, application of general, scientific knowledge required adolescents to manage life in a fairly rigid way. Sam explained:

Like, umm, you get used to it pretty quick I think but even then it's still kind of – they force the routine on you a bit too much. Like, if I looked back and I was getting trained now, maybe this is the reason why teenagers have such trouble dealing with it is that, like forcing that kind of routine on someone who's in my situation would not work. It wouldn't work, it wouldn't work for me if someone tried to get me testing 4 times a day, ah, carrying like, carrying extra food every single place I go, like, umm, accounting for every like amount of food I that I ate and all the insulin, everything, I think it would just be like, people my age would be like 'forget that', like it's not worth my trouble.

Over time, this rigidity, based on science, relaxed as individuals internalized the scientific knowledge and came to understand how to fit that knowledge into their everyday lives. The science then faded into the background, yet continued to provide the basis for many of participants' everyday decisions. However, participants recognized that scientific knowledge has limitations. One participant explained her frustration with such limitations in the context of trying to lose weight. In this situation, there was conflict between the scientific knowledge guiding diabetes management and the science guiding potential weight loss. Health care professionals advised her based on the principles of weight loss without consideration of her frequent hypoglycemic episodes that

necessitated extra food and sabotaged her attempts at losing weight. In the following excerpt, she illustrated:

Yeah, they [health care professionals] just said to eat healthy and everything but I don't know, it just seems after a sport or something I'll have to come home and have like a light snack but then I'll be waking up in the middle of the night and having to have something else so it's just kind of, like hard...I guess it's just because I play a lot of sports so, it makes me have to eat more, for bedtime snacks and stuff, I won't be hungry but before I go to bed just to make sure I get through the night I'll have to have like a snack ....the thing that is hard to deal with is protein...And that's for fattening stuff, like say if you want peanut butter or you need carbohydrates, like, it's just harder because you always have to make sure you are eating.

Although scientific knowledge can be self taught and actively sought, the reality is that it is health care professionals who, at the outset, control the nature of diabetes education, and decide what scientific knowledge individuals with diabetes require. Important aspects of scientific knowledge include not only what is taught but also what is not taught to adolescents either at the time of diagnosis or at a later date. For example, many participants had no knowledge of using insulin to cover high-sugar foods and were quite reluctant to do so. And, while Alyssa explained that she chose not to do so despite health care professionals encouragement, this was not the case for several other participants who maintained that they had never spoken to their health care professionals about this issue. Furthermore, one participant noted the inconsistency between his Mom's advice to adhere to scientific principles and his Mom's response to his doing so. He explained:

Yeah, like um, it's like my parents they always, my Mom specifically, she's always 'you can't have a "slurpee" unless you do like blah, blah, blah hours of physical activity' and I'm like 'Okay, fine' and then I come home with a "slurpee", she starts yelling at me and I'm like 'Yeah, I just went biking for 3 hours so I'm allowed to'. (Lots of laughter) But, yeah, I can work it in that way so it's not as big a problem.

In summary, adolescents attended to scientific principles by gaining scientific knowledge. Participants acquired much of their scientific knowledge from the health care professionals with whom they maintained regular contact. The majority of scientific knowledge acquisition appeared to occur at the time of diagnosis although there was ongoing dialogue and contact with the health care team. Presumably, the scientific principles on which participants based their decisions remained relatively stable because such principles did not acknowledge the context of adolescents' lives. For example, while individuals may vary their management strategies because of varying contexts, the scientific principles that inform them that food increases blood sugar levels and exercise and insulin decrease them are crucial principles to understand and, in general, remain unchanged regardless of the context of individuals' lives. Despite this limitation, participants continued to use their scientific knowledge to help them make decisions that were relevant to both the present and the future.

#### Preparing for the Future

An important theme in participants' discussion of scientific principles involved their recognition that these principles provided a basis for knowledge about how current actions might affect their future health. Surprisingly, given the assumption that adolescents are concerned with the present rather than the future, worry about diabetes-related complications in the future was in the minds of many of the participants and had a significant impact on everyday decision making. Worry about the future and fear of complications was based on knowledge that was presumed to be scientific. Specifically, everyday decisions around food choices were often made based on the desire to avoid future complications. Also, if food choices were made that were incongruent with optimal blood sugars then other strategies were sometimes put in place such as exercising after

eating the food that was likely to cause hyperglycemia. Some of the adolescents had heard "horror" stories of individuals with serious diabetes-related complications and one adolescent explained that his Mother's response was " 'If your blood sugar goes high I don't want to be the one to have to give you my kidney' and stuff like that. But she said she will." In the following excerpt, Ivan explained his viewpoint, which represents several participants' thinking:

Participant: But I know that I'd rather – in the long run I know that it's better to have low blood sugar than high blood sugar cause if it's a controlled low – like maybe 3 or high 2's that's fine. [optimal blood sugar range is between 4-7 (Meltzer, S. et al., 1998)]. You eat and you get better but if my blood sugar gets up into the 15's – 20's and, on the rare occasion 30's, which is terrible, then I can get into some problems with my eyes, my heart, my – I can't remember some of the others and my kidneys

Researcher: Now does that ever worry you – do you ever think about that?

Participant: Yeah, so it's stopped me quite a bit before I'm doing it but sometimes it hasn't and I'm just extra active when I do it.

Sam had a different perspective which he shared when asked if he ever thought about possible long-term complications and if such a possibility had any impact on what he did on a day-to-day basis. He explained:

Not really. Like I, I don't worry about the long-run so much as I do about the short-run because like if I'm going to live I might as well live having fun now so, like I'm not going to be one of those people, who's like, going to do like, 'Okay, I'm doing 30 minutes of physical activity at 3:30 in the afternoon exactly so that my blood sugar doesn't go too high' and - I'm not going to take it to an extreme level like that; I just want to live a normal life as well I can - and if that means that I'm going to have slight health problems in the future like I can't be for sure I will so - I think I've dealt - I think I've worked with my diabetes well enough that I'm not in too big a danger of having it. Like my hemoglobin's gotten pretty high and I've been working on that to reduce it so I do care a bit about what happens, I just don't - I don't want to be affecting my - my future health that badly but I'm not going to, like be rigorous in my take extreme measures to make sure that I - to make sure that I stay within the exact hemoglobin range kind of thing. I'm not - I'm not overly worried about future consequences. I know they're there and I know they could be a problem but I'm not going to change my whole regular life, like I'm not - I'm not going to change, like every three hours that I wake up on the weekend so that my insulin works better just because, just because, like in the

future I might have kidney problems, right? Because I'd rather - I'd rather stick with my normal schedule and deal with it based on that than do it the other way around.

In summary, several adolescents used their scientific knowledge to prepare for the future by recognizing that current everyday decisions had the potential for negative consequences in the future. Although some adolescents were not prepared to make extraordinary changes to their current lives to prevent these potential consequences, several participants explained that many of their everyday decisions were based on preventing or treating hyperglycemia and thus aimed at minimizing the risk of future complications. Such preparation is interesting given the assumption that adolescents pay minimal attention to future events.

#### Developing and Adhering to Routines

In addition to the use of scientific knowledge, participants attended to scientific principles by developing and maintaining prescribed routines. Routines, particularly those in the morning, were very structured and followed a similar pattern each weekday. In a sense, because of school and other weekday commitments, maintaining a regular routine was relatively unproblematic on school days. The following excerpt exemplifies a typical weekday morning for many of the participants:

Weekdays – I wake up, like this past year, I was waking at about 6:45 and I'd do a blood test right as I woke up then depending on my blood test I'd change what I was doing next. Like if I was lowish then I'd like go get some snack, go get some sugar and then have insulin, breakfast and then I'd go out and shower and get ready for school. But if not I'd just do a blood test and have a shower and get ready for school and then go have breakfast and then I'd leave for school. And then in the morning I'd have my morning snack, at lunch I'd have lunch , come home from school have an afternoon snack and during the course of the day like I don't test or anything, like I don't have a blood test machine with me 24.7 but I do usually notice when I'm low so I don't have problems with that usually. And get home have a snack, do blood test and then do homework, whatever I have to do in the afternoon, insulin, dinner and then do whatever I have to do at night – homework, that type of thing or depending on – sometimes after school I have mountain bike racing or baseball, stuff like that but usually not at night but then at

night I'll be usually doing homework, reading, that kind of thing. And then do blood test, have snack and go to sleep and do the same thing next day (slight laugh).

Weekends were different and maintaining similar routines was somewhat more onerous. Nevertheless, several participants maintained a structured routine on weekends even though it meant being unable to sleep-in the way that they would have liked. Sam differed from others in that he played around with his weekend schedule and fit diabetes into the weekend's happenings, although he recognized that his blood sugars were somewhat unpredictable as a result. He also worked with his insulin to accommodate his weekend needs and described "splitting" his long-acting insulin dosages in order to maintain his insulin levels. Some of the other participants believed that there was no alternative to rising at 9:30 AM in order to maintain insulin levels. Consequently, most participants adhered to scientific principles on weekend mornings despite its undesirability and lack of flexibility. Besides broad daily routines, participants maintained specific routines and made everyday decisions that were based on their scientific knowledge of food, exercise, and insulin.

### Food

Several participants identified issues with food as one of the biggest hassles related to living with and managing diabetes. It was problematic for individuals when they were unable to eat despite being hungry or forced to eat when anorexic. In addition, it was difficult for adolescents not to be able to eat the types or amounts of food they wanted and the relative inflexibility of nutritional science meal planning was challenging, particularly in terms of portions. However, there is no doubt that there was considerable flexibility in terms of mixing and matching food choices within the guidelines of prescribed meal plans. Some participants used food exchanges as a means of guidance;

others had used carbohydrate counting in the past; and others used no formal scientific nutritional framework to guide their decisions around food choices. Ivan explained how it worked for him, as the following excerpt illustrates:

Researcher: So, do you sometimes just kind of like second guess – well, you kind of have a milk but instead you want something else so do you or is it very scientific? How does it work for you?

Participant: I'll go off the wall sometimes. I know that it goes: a fruit is the quickest acting; a starch is the second and milk, protein, fat. So, I'll never substitute, like a fruit for a fat. That's the dumbest thing cause that just won't work, but I will on the odd occasion swap, like – I don't know – maybe some popcorn for an apple – well it would be the other way around but an apple for some popcorn and if I'm supposed to have milk and it's – well, milk is a bad example but if I'm suppose to have fat I might have something with milk in it or something like that. I'll always swap but only for something close to it and for something with about the same amount of calories in it the other thing has.

Food was used to satisfy hunger in general (though not always effectively), to provide energy during activity, to treat lows, and to prevent lows especially during activity. There was a lot of emphasis on food and, in some of the "Think-Aloud" entries, decisions around food were the only decisions shared. Also, Ivan talked about making choices based on foods being "allowed", and he explained that his decisions were based on whether a food option fit into his meal plan. In addition, adolescents sometimes used scientific knowledge to make decisions around the type of foods chosen at particular times of day. Sam explained his rationale for using protein in the morning meal plan:

I've been keeping my food about the same, uh, minor variances but I'm sticking to my normal meal plan like, uh, afternoon snacks are basically the same – like popcorn or like cookies but I'm trying to remember to fit protein in the morning some days because the days that I wake up low I'm trying to fit protein in so that I make sure I don't drop later on in the day so I'm doing that as well.

Generally, participants maintained fairly consistent routines around food and meal plans and described regular meals and nighttime snacks. Decisions around food were often based on blood sugar readings, with low blood sugars offering opportunities for

extra food or different food options and high blood sugars sometimes resulting in decisions to increase insulin or reduce food. Some participants were reluctant to reduce food at breakfast time even if blood sugars were high so there was a tendency to maintain a consistent breakfast even in the presence of high blood sugars and to increase food intake if low. Adolescents sometimes talked in term of “bad” decisions and these decisions were usually related to food choices. Sometimes, certain foods were seen as being unconditionally “bad”. At other times, as the following excerpt illustrates, Ivan recognized that decisions were made in the context of his life and were, therefore, not always perfect. He explained:

Em, then when I got home I went for a roller blade with my friend for my afternoon snack and I got a bag of chips and a pop. Now, I think that I could have made that a bit healthier, it wasn't the best decision I could have made but em, it's Friday so I gave myself a little bit of a treat and plus I went for a roller blade so not the healthiest thing I could have had but I found I compensated for it quite well.

One participant maintained that she would not choose high sugar foods when her blood sugar was high yet she later explained that she chose a regular pop when her blood sugar was 15. In trying to help me understand her reasoning behind such a decision, she explained that she had less food, less of the pop, and an activity later on in the afternoon. On further exploring this reasoning, she agreed that perhaps there was also an element of knowing and not doing. Carrying food was used consistently as a precaution against potential low blood sugars and participants devised ways of ensuring that high sugar foods would be available to them should they need it. Food was kept at bedsides, in glove compartments, in purses, and on person. Finally, patterns were often cues to make changes around food. Essentially, adolescents often decided to increase food intake if there was a pattern of lows, particularly involving exercise. Such patterns, particularly patterns of lows, enabled participants to identify the effects of exercise on their blood

sugar levels and were useful guides to making changes in food decisions in order to prevent or treat low blood sugars.

### Exercise

With the exception of Roger, all participants were involved in exercise or physical activities of one sort or another. While adolescents spoke mostly of exercise in the context of diabetes, it was clear that some participants were involved in sports because they enjoyed the particular activity or as a means of staying in shape.

Adolescents often planned quite carefully in advance for activity in that they lowered insulin dosages, increased food intake and carried extra foodstuffs. The intensity of anticipated activities was an important component to consider when planning a management strategy. However, planning in advance was sometimes difficult, as it was not always known what exercise might occur when choosing insulin dosages in the early morning. The trial and error decision making that followed usually required compensating for unplanned activity by increasing food intake. Sam explained:

Researcher: Do you have a fairly good sense of – say if it's an hour activity – that you lower your N [NPH is a long-acting insulin given twice daily]. The morning N would likely peak in the afternoon] by 2 [units] or whatever or if it's a two-hour? – do you have a sense yourself of how much to lower it or is it a bit of a hit and miss type of thing? Trial and error?

Participant: It's a bit of a trial and error kind of thing because like my main sport's mountain biking and I don't know when I leave how long a trail I'm going to do or how long I'm going to be biking for, that kind of thing so like, like ah, it was a couple of weeks ago I went biking on Mount Seymour and I thought we were just going to do like a short trip and I ended biking for 5 hours so – like I had a chocolate bar, a “slurpee”, plus my snack and I was still normal when I came home. So like I did. I did compensate but I didn't compensate enough because if I was normal when I came home and had that much sugar that (laughter) it shouldn't have worked so. But like that's a kind of thing where the situation changes so I have to do something to make sure I don't go low.

In addition to preventing hypoglycemia during exercise, some participants preferred to increase food intake as a means of providing energy whereas others preferred

to reduce insulin. Yet, sometimes even omitting, rather than simply reducing, an insulin shot did not prevent hypoglycemia, as Hayley's experience illustrates:

Yeah, cause when I usually, when I play sports like basketball I usually don't take any insulin that night because, or I usually, I always wake up in the middle of the night and that's really weird. Just, like, say if that I have basketball game at like 6:00 I won't take any insulin because I usually still wake up in the middle of the night [low] even if I don't take insulin.

Adolescents seldom checked their blood sugars because of activity, although Sam recalled that he had done so in the beginning, thus illustrating his reliance on the science of technology in the early days of his illness trajectory. He explained:

Yeah, I did bring a blood sugar machine with me when I kind of first started biking because I guess we weren't sure like how it would affect everything but now I think I've got a pretty good sense just of myself of when I'm going low so usually I can figure it out myself and I'll 'Okay, lets just sit down for 10 minutes and I'll grab some sugar and snack and I'll be fine.'

Although participants planned for exercise with the assumption that activity might lower blood sugars, when this happened they were sometimes unaware of it as they were distracted by the activity. Interestingly, participants reported that hypoglycemia was less common than was hyperglycemia during intense activity. Nevertheless, several participants recognized the tendency for blood sugars to drop later, particularly overnight as was often the case for Hayley and Samantha. Consequently they were mindful of this phenomenon as they made their decisions around exercise. Not only was food used to compensate for increased or unplanned exercise, but adolescents sometimes used exercise as a means of lowering blood sugars. Ivan explained:

I'll use an example. I knew my blood sugar was really high this one time and I tested and it was 20-something, So I got my roller blades on and I really like skating cause I play hockey and everything so I'm really good at that and I just – I can never just go for a skate – I need a goal so I went to the store and I got a diet pop and I drank that while I was skating. I skated for a good half hour and I came back and even while I was doing the skate I just felt great and my blood sugar was back down – I think it was 8 – so skating or soccer, hockey always brings it down.

In addition, exercise was sometimes viewed as a legitimate way of having high-sugar foods. However, there was a price to pay and Ivan graphically described the incredible amount of work that it entailed in order for him to have a “slurpee” and he realized that it just might not have been worth it. He shared his perspective:

Like the first thing I ever tried was a “slurpee” – because pretty much everybody I know – knew had it and they all said how good it is and so I hatched this plot – that I’d take away a fruit from lunch and I wouldn’t have an afternoon snack, then I’d go and get the smallest size “slurpee”. My blood sugar was about 10; I was fine – I was quite confident in myself but the amount of work I had to do for it – always make sure you’re ready to work – so I said ‘if I’m going to do this thing, I’m going to work’. So I had it, while we were roller blading around my block for about an hour and then I came home, tested my blood sugar – 8. Okay, I’ll leave it just to see if it rises, so it goes up to 9 – I got on the exercise bike for about  $\frac{1}{2}$  hour, it stayed down and then I kept working just to make sure it didn’t go up and after I was done my blood sugar was stable again. It wasn’t going up – it wasn’t down or anything. I just fell back and all the work that I’d done for that small “slurpee” and I realized that, as good as the “slurpee” was, it wasn’t really worth it. So if you’re going to do something make sure that you work hard and just make sure that it’s worth [it].

This example illustrates Ivan’s attempt to adhere to scientific principles despite having what would, in all likelihood, be frowned upon in the scientific realm of food planning.

### Insulin

Adolescents regularly made decisions that attended to the necessity of balancing choices involving insulin, food, and exercise. Depending on the particular context, decisions were made based on either one or a combination of these elements in addition to factors such as hunger. However, there is little doubt that the majority of insulin decisions were made on the basis of blood sugars.

Adolescents reviewed insulin dosages when they detected a pattern of non-optimal blood sugars and often decided to adjust insulin or increase food intake based on noted patterns. In fact, it was quite problematic to make decisions if patterns were non-

existent or erratic. In the absence of patterns, decisions were often limited to those involving short-acting insulin, which was sometimes decreased if blood sugars were low and sometimes unchanged while food was increased. Some participants increased insulin for high blood sugars and for extra food at mealtimes but rarely for high-sugar foods. Others made no insulin adjustments for high blood sugars; instead, they chose to decrease their food intake. Insulin was sometimes reduced for new or high-risk situations (e.g. driving or social events) as a means of preventing low blood sugars even if such decisions resulted in blood sugars that were a little higher than might be optimal. Generally, insulin was not increased for an anticipated quiet day; instead, food would be decreased. The exception might be an unusually quiet situation such as flying which involves a great deal of inactivity.

There was variability when planning for known activities in that some participants maintained insulin dosages and increased food intake, whereas for others, insulin was decreased for planned activity. Sometimes, participants chose one decision in a particular context and a different decision in another context. It was often unrealistic to plan in advance, as activity was not always anticipated at the time when insulin was being given. The following excerpt illustrates the difficulty associated with advanced planning, "So, it's kind of hard to judge – like, sometimes it [activity] will be like early afternoon, late afternoon. So, I just control that more by testing and by ah, food intake."

Sliding scales were frequently used to guide decision making although their use provided a guide for short-acting insulin only and did not account for anything other than blood sugars. In general, sliding-scale insulin means that insulin is adjusted according to single blood sugar levels (Hirsch, & Farkas-Hirsch, 2001). These authors maintain that the use of sliding scales is very limited and they explain that, with the exception of

insulin use, the contexts of diabetes management, such as food intake, are ignored. In the current study, neither exercise nor the complexity of having to consider long-acting insulin was taken into account when using sliding scales. Despite such limitations, adolescents found sliding scales to be a useful tool to guide insulin-dosage decision making. In addition to tools such as sliding scales, participants appreciated new products that facilitated flexibility in their decision making. For example, some participants noted the great convenience of Humalog, the latest rapid-acting insulin on the market. The swift action and short duration of this insulin allows for considerable flexibility and Grey, Boland, and Tamborlane (1999) suggest that Humalog (Lispro) may be particularly suitable for adolescents' lifestyles. Over time, participants developed a less rigid attitude towards insulin scheduling, as the following excerpt illustrates:

But when you first are diagnosed you kind of like 'Okay! It's 5:00 – I have to do my insulin right now!' And I always did it like right on 5:00 but now I realize I can kind of like, it's not so, I mean it is like on a very strict\_type of thing, but it's not as strict as I thought it would be. So, I'm kind of more flexible with it and I don't worry about it as much.

However, as previously mentioned, while most adolescents gave their insulin a little later on weekend mornings, they believed that they had little flexibility around early morning insulin schedules at the weekends and this was noted to be quite bothersome. Sam, on the other hand, was quite flexible and creative but found that his blood sugars were unpredictable as a result. He explained:

Weekends too, I'm up later cause I'll be out with friends or whatever, stuff like that so um if I'll wake up about 11:00 or whatever and that's always interesting because I have to test and usually I'm like high or low or not normal because my – all insulin and everything got messed up because I'm messing around with my schedule and then I have to figure what I'm going to do that day and adjust my insulin and everything because I'm not going to be having 3 meals because I'm waking up at 11:00 and it's almost lunch time so I have to deal with that.

Researcher: Do you change your insulin a lot to compensate for different scheduling on weekends?

Participant: Yeah, usually like, umm, if I'm going to be biking for 3 – 4 hours its going to be intense so I'm going to have to change it, I'm going to have to lower my N probably in the morning by 2 – 4 units because if not I'll end up going low and being low in the middle of Grouse Mountain is not a good idea so um adjusting my insulin, yeah, I have to play around with it and then the other thing I do is split my N at night if I'm going to be waking up late the next morning.

Researcher: So, when you say you split it – what do you mean?

Participant: I take humalog, regular, and NPH insulins, umm both in the morning and at night so what I do at night is I'll have my humalog and regular with my dinner and then around my bedtime snack or before I go to bed I'll have N and that way when I wake up in the morning I won't be as high usually because the insulin runs out and I'm always high in the morning because I'm sleeping longer.

Researcher: But you only do that on a Friday or Saturday night?

Participant: Yeah.

In addition, giving insulin at a time when he usually did not give it, namely late afternoon, allowed Sam a sense of control that was very positive. He described his perspective:

My current dosages seem to work and, like afternoon highs are [less] of a stress now cause just 'okay I'll take insulin and that way there'll be no problem, right?' And it's good to be, for like my doctors and such to say 'don't worry so much if you're high after school because if you take insulin then your blood sugar. Instead I'd always, before I'd come home high and it would be like 'Great! Nothing I can really do!'

On the other hand, such control was less attainable for the younger adolescents as they relied heavily on parents to make many of the insulin-adjustment and insulin-dosage decisions on their behalf. Consequently, they experienced difficulty in terms of spontaneous socializing with friends as they needed to carefully plan in advance for such outings.

In summary, participants developed and adhered to routines that were based on scientific principles. Not surprisingly, given the context of adolescents' lives, maintaining

such routines was less onerous during the week as opposed to doing so during the weekend. Nevertheless, participants, for the most part, did adhere to these routines, thus illustrating their use of scientific principles despite the challenges they faced in doing so. In addition to the general routines related to the structure of their lives, participants maintained routines that were based on their scientific knowledge of food, exercise, and insulin. Also, as was true for adhering to general routines, adolescents often maintained specific routines around food, exercise, and insulin despite the challenges that this entailed. Although there were challenges associated with maintaining scientific routines there were also benefits, and adolescents often appreciated the guidelines that science gave them in their everyday decision making.

#### Blood Sugars: Science Lends a Hand

With the exception of Roger, all adolescents routinely checked blood sugars three times daily and based many of their decisions on the results of these checks. Basically, glucometers were viewed as useful tools and the ability to check blood sugars was used as a way to prevent hypoglycemia, confirm symptoms, recognize potentially problematic levels, identify patterns, calculate food portions, guide activity choices, and finally, guide decision making and maintain safety in new or unusual situations. Furthermore, blood sugar checking was a way to validate the wisdom of earlier food decisions. Alyssa confirmed this, saying, “I had a piece of chocolate cheesecake – So it was a good decision because umm, my blood sugar wasn’t high – it was perfect, it was 4.” She also used it as a means of calculating the types of food to have so that high blood sugars might be reduced and she explained:

My blood sugar was a little on the high side so I don’t want to eat something that has too much sugar so a salad would be a good choice with vinegar. I felt okay about my decision. I didn’t have a hard time. I knew what I wanted and I knew

that I was high and I knew that I needed to bring my blood sugar down. I would make the same decision again because my blood sugar was good after I had that.

Most adolescents did not do a blood sugar check at lunchtime as it was quite inconvenient, particularly at school. However, they were often willing to do so for a limited period of time, often on the advice of health care professionals, and for a specific reason such as detecting blood sugar patterns at this time of day. Adolescents sometimes tried to understand the reason for high blood sugars but seldom did so for low blood sugars. Most adolescents had a "feel good" range and while this was variable it was more so at the high rather than low range. Several participants identified 4 – 8 as their "feel good" range. There was a fairly wide range when adolescents were asymptomatic, particularly in the high range, and they recognized that this was problematic as it frequently went undetected unless discovered by a routine blood sugar check. Adolescents were sometimes surprised by the results of routine blood sugar checks, and discovering highs in this manner was not unusual.

Discovering undetected lows did happen on occasion but was relatively uncommon. Hayley was unusual in that she found it harder to detect low blood sugars over the years whereas most of the others found that time lived with diabetes enhanced their ability to detect low blood sugars, although there was certainly a degree of variability with individuals as to the level at which they felt low. Adolescents tended to do more blood sugar checks for suspected hypoglycemia than for suspected hyperglycemia and in the former they were generally quite accurate. In a sense, this is not surprising as participants' ability to suspect and detect hypoglycemia was more finely tuned than the ease with which they detected hyperglycemia.

Participants described a variety of symptoms that alerted them to alterations in their blood sugars. Some signals are textbook examples of alterations in blood sugars

such as feeling shaky, an inability to think clearly, low energy, (indicating hypoglycemia); or fatigue, extreme thirst and frequent urination (indicating hyperglycemia). The latter, for most participants, was more challenging to recognize.

One participant confirmed this, saying:

High is not as easy for me to figure out as when I'm low but I still will notice some things, the main thing is thirst, if I'm really thirsty I'll think 'wait a second – if I'm this thirsty' cause like I have like two glasses of water or two glasses of pop or something like that and I'm still thirsty, then I start thinking 'wait a second – I'm probably high' or if I'm really hot, like my head is just red and really warm feeling, ah, I just get this feeling like my ears are red and my whole face is just like red – like hot – just like a hot feeling that I get and it just feels different than I normally would if I was just walking down the street so it's a different feeling than I have when I'm high but its not as noticeable like I won't notice it in the lower high range just like when I'm pretty high – Oh, probably around 20-22, around there.

In summary, blood sugar levels played an important role in everyday decision making. The majority of participants checked their blood sugar levels three times daily and found the glucometer to be a useful tool in facilitating decisions about food, exercise, and insulin. Overall, the science of everyday decision making is one of the three themes identified in the findings of this study. While "the Art and Science of everyday decision making" creates a semantic rhythm and flow, it was necessary to consider the science before the art, as the former preceded the latter in the context of participants' lives.

The science of everyday decision making was made up of a number of sub-themes: gaining scientific knowledge; preparing for the future; developing and adhering to routines; and blood sugars: science lends a hand. These sub-themes were inter-related and were based on adolescents' use of scientific principles. The scientific principles and knowledge that participants used were closely associated with health care professionals' teaching and the information that was given to adolescents and their families, particularly at the time of initial diagnosis. There was an assumption that much of the scientific

knowledge that adolescents required was relatively stable and this was not surprising given the notion that scientific knowledge was somewhat acontextual and general, thus ignoring the complexities of adolescents' lives. Therefore, it makes sense that the art of everyday decision making follows the science as the latter laid the knowledge foundation on which adolescents were able to build in order to artfully apply generalities to the specific contexts of their everyday lives.

### **The Art**

In contrast to the science, the art of everyday decision making recognized and was embedded in the context and uniqueness of participants' lives. Acquiring experiential knowledge and artfully applying knowledge (both experiential and scientific) to their everyday lives constituted the art of everyday decision making. This second theme relied somewhat on the first theme of science, as the latter provided a foundation on which adolescents based some of their artful decisions. The experiential knowledge that adolescents gained as they lived with diabetes complemented the scientific knowledge that they already had. Their experiential knowledge sometimes challenged the limitations of science and so, participants learned, over time, to make decisions that were sometimes based solely on science, sometimes solely on art, and sometimes on both the art and the science.

While participants' body signals constituted the science in that they represented physiology, responding to such signals, as presented in this section, constituted the art. Similarly, the sub-theme of blood sugars: science lends a hand was conceptualized as a science whereas participants' comfort with highs and lows was more closely aligned with the art. Furthermore, just as participants used scientific guidelines, so also did they develop unique and personal ones. Finally, learning from experience emphasized that,

unlike the science, the art is not static. Rather, it is more of a process; changing, ongoing, and somewhat unique to individuals and the lives in which they enact the art of everyday decision making.

### Responding to Body Signals

Participants' responses ranged from knowing and listening to body signals to an inability to hear such signals. Further, adolescents sometimes trusted such body signals and sometimes they needed to check them. Over time, individuals came to know their bodies' responses to physiological changes, specifically changes in their blood sugars. In particular, participants were acutely aware of low blood sugars and felt very comfortable with their ability to detect low blood sugars. Feeling comfortable with their ability to detect low blood sugars permitted adolescents to trust their body signals, thus allowing them to go ahead and treat as appropriate. "Appropriate" treatment was usually based, at least in part, on scientific knowledge (i.e. simple sugars to treat a low blood sugar followed by a longer-acting food such as protein). The longer-acting food was not always used, as participants had learned from experience that it was not always necessary. In the following excerpt, Ivan described his experience with knowing his body's responses to a range of blood sugars, saying:

If I'm low I can just tell right away – I'm hungry, I'm energyless and I shake a lot, Yeah. I just start twitching like this, and I can't control it and I just can't think – I can't see, like I get a little bit blurry. That's only if it gets really low, so things aren't clear enough and so once I feel one of those things I know I have to eat. Except the hunger one – that one's kind of depending, but usually that one goes along with something else and if I'm high I'm tired, I'm really, I don't know if I do but I feel like I'm getting really pale and I feel really warm and so then I know that I need to run around a lot and if I'm normal I just feel great!

Even so, in addition to listening to and trusting body signals and their interpretation of such signals, participants often checked their blood sugar with their glucometer. The use of a glucometer, as discussed earlier, illustrates the merging of

science and art as science figuratively “lends a hand”. Adolescents were almost always accurate when they checked signals that alerted them to a low blood sugar. Their accurate interpretations further validated the reliability of listening to and trusting their own unique body signals. Sometimes, participants treated themselves based on their body signals and relied totally on such signals as their cue to continue or discontinue their management. At other times, adolescents checked their interpretation of such signals with their glucometer usually after initiating some form of management for hypoglycemia. They used either a “treat and test” or a “test and treat” approach. Sam confirmed this, saying, “Yeah, I’d test first. Even if I do have some symptoms I’ll probably test first. If it’s bad and I know it’s bad I’ll take juice first and ask questions later.” The availability of a glucometer often determined whether or not individuals used these approaches. If one was unavailable, then a “treat-only” approach was used.

Participants who experienced frequent nocturnal hypoglycemia explained that they sometimes checked their body signals with a glucometer so that they could determine the precise level of their blood sugar and, in so doing, avoid over-treating a low blood sugar that might then result in high blood sugars in the morning. They based these strategies on previous experience with such events. Two adolescents who experienced frequent nocturnal hypoglycemia were fortunate in that they always woke up with feelings of hypoglycemia; their bodies alerted them to their hypoglycemia and they were able to manage accordingly. Hayley often checked and treated nocturnal hypoglycemic episodes, but did not do so during daytime episodes of hypoglycemia. She explained:

Umm, I usually only check in the middle in the night; I can tell when I’m low during the day, like it was at school and like I could just tell – I’d maybe have like some juice or a candy or something, like I wouldn’t check, like you’re not at home, it’s not like your comfort zone kind of thing and it’s like well you’re

already busy doing something else. I never really think it's a big deal, I would just have some juice and I'll be fine.

Unlike Hayley, Samantha usually treated her nocturnal hypoglycemia and went back to sleep without checking, as she trusted her body signals. Samantha experienced frequent bouts of nocturnal hypoglycemia and, interestingly, when asked if her Mom or her physician encouraged her to check her blood sugar, she explained that they did not, thus highlighting others' trust in her ability to reliably use body signals.

Furthermore, low blood sugar signals were not always "working" or perhaps "noticed" or "listened to" and participants were occasionally surprised to discover a low reading when they did a routine blood sugar check. Blood sugar checking was used more often in the earlier days of their illness trajectory, not only to detect blood sugar levels, but also to check body signals. Recognizing and trusting body signals developed and improved with time and experience. In addition, Ivan explained that very low blood sugars could have been avoided if he had listened to, rather than ignored, the signals that his body had given him regarding moderately low blood sugars. He identified that "just light shakes and light symptoms, usually about 3's and when it's extremely heavy you get really heavy and you just feel like going to sleep. That's when it's getting out – getting into about the 2's....It progresses if you ignore it." He agreed that this sometimes occurred because he was busy and did not have time to pay attention to his body signals.

While body signals were used consistently to determine low blood sugars this was seldom true with high blood sugars unless they were above 15 or so. There was a wide range when many of the adolescents were symptomless and they recognized that this was potentially problematic in terms of decision making, as some participants were often unaware of moderately high blood sugars. One participant agreed, saying:

I usually tell just by myself what my blood sugar is – like I know when I'm high and know when I'm low. But I only know at the extremes so not too much in between, so I guess I use the glucometer as a tool to help with the decisions where it's kind of in between, where it's in between like a peak high or a peak low, and being normal.

Decisions were seldom made around these potentially problematic blood sugars unless they happened to check a blood sugar and discover that they were indeed high. Adolescents varied in terms of the level at which they experienced hyperglycemic and hypoglycemic (especially the former) symptoms or signals. However, once they did experience signals of hyperglycemia, adolescents often made a decision to exercise, to eat less or differently, or to take insulin. Again, as was the case with hypoglycemia, participants sometimes based their decisions on signals alone, sometimes checked their blood sugars, and occasionally discovered the high or low blood sugar during a routine check.

Adolescents also talked about the difficulties associated with being unable to act on body signals. Specifically, it was quite common for them to be forced to eat because of hypoglycemia even though they were not hungry. Conversely, despite being hungry, adolescents bemoaned not being able to eat when blood sugars were high. Therefore, adolescents had to be very selective as to what body signals they listened and responded to, what signals they could trust, what signals they needed to check, and what signals they had to ignore. One participant explained:

The other thing I don't like about diabetes is like sometimes you have to eat when you're not hungry. I want to lose weight a little bit so I don't like that cause it's like you're eating but you don't need to be eating kind of thing and that gets annoying. Or when you're hungry and you can't eat – it gets kind of confusing.

When adolescents based decisions on body signals they sometimes evaluated these decisions on later blood sugar readings. For example, at nighttime, Hayley and Samantha explained that, in the past, morning blood sugar readings helped them to

determine whether they had “overtreated” and misinterpreted the specific level of their hypoglycemia. They never doubted that they had had a hypoglycemic episode but acknowledged that it was very challenging to determine its exact degree by body signals alone. Similarly, Alyssa’s experience with, and positive evaluation of, decisions that had been based on body signals is illustrated in the following excerpt. She explained:

I decided to have a chocolate bar after school and I guess I decided it because I was feeling a little shaky so decided to have something with a bit more sugar. Umm, I really didn’t talk to anyone about it because I was sort of alone so I really didn’t have anybody to discuss it with. And, I have been in this situation before when I have been shaky and I have wanted one or not exactly wanted one but knew I needed something and so I had a chocolate bar before and so it did help me decide or, being in that situation before did help me decide to have something. And, I feel okay about my decision like when I came home I tested my blood and my blood was fine, it was, I believe it like 8, 8 point something....I’d probably make the decision in the future and, Umm, it wasn’t, it wasn’t really a situation that I haven’t done before but it was kind of easy so, because I’ve done it before. And it was a good decision because I tested my blood sugar and it was good.

In summary, participants’ responses to body signals depended on past experience with such signals, the stage of their illness trajectory, the availability of blood sugar checking devices such as glucometers, the convenience of using such devices, and their own confidence in their ability to reliably use body signals. Essentially, participants’ responses to body signals meant that adolescents knew their unique signals, listened to them, trusted them, and, when necessary, checked them. However, while usually dependable, body signals were occasionally “not working” or adolescents were unable to “listen” to them. Consequently, participants were sometimes surprised by the results of blood sugar checks. Participants were able to detect the body signals associated with hypoglycemia much more easily and accurately than those of moderate hyperglycemia. Adolescents’ ability to reliably use body signals improved over time and, in addition to the adolescents themselves, others, as Samantha’s experience illustrates, had confidence and trust in their competence and expertise.

### Comfort with Highs and Lows

Generally, most of the participants preferred to avoid low blood sugars and although they recognized the implications of high blood sugars they also understood that those implications were less acute than the consequences of hypoglycemia. Samantha was the only one who, if she had to choose, preferred to avoid high blood sugars. Interestingly, she was also the only participant who had never experienced a significant hypoglycemic episode. The symptoms related to hypoglycemia were undesirable and, presumably, the “symptom-less-ness” of moderate hyperglycemia meant that adolescents felt more comfortable when their blood sugars were high than when they were low. The notion that they did not have symptoms and were, therefore, unaware of their blood sugars levels meant that it was unrealistic to do anything about it. One participant verified this, saying:

I don't worry so much if I'm in the twelve's .... if I'm really high up then I start to feel really bad. Like I'll start to feel like, not great, not wanting to do much of anything but if I'm around 12 I'm still normal like I actually don't physically feel different than if I don't physically feel that I'm high. So I just think I'm normal so I really won't react or change anything because of that.

Sometimes, adolescents made decisions in order to avoid raising their blood sugars in the first place thus illustrating a health promotion cycle within their self-care management strategies. In addition, some participants preferred to be cautious in unfamiliar situations and preferred to maintain their blood sugars at a higher than optimal level. In this way, they maintained their sense of safety and avoided hypoglycemic episodes.

In summary, participants' comfort with highs and lows depended on past experience and the body signals or symptoms associated with blood sugar levels. Generally, most participants preferred to avoid low blood sugars as the symptoms

associated with hypoglycemia were particularly undesirable. For this reason, adolescents, in new situations, often maintained their blood sugars at higher than optimal levels. Participants recognized that there was a paradox between the acute consequences of hypoglycemia, the visibility of such consequences, and their ability to detect or prevent such consequences versus the potential and somewhat invisible chronic consequences of hyperglycemia.

#### Developing Unique and Personal Guidelines

Adolescents developed their own unique and personal guidelines and these were often as a result of science's shortcomings, a desire to maintain safety, fit diabetes into their lives, and continue to live life as adolescents. Some of these guidelines appeared to simply evolve. In particular, almost all of the participants described their weekend schedules as being more relaxed than during the week, and therefore they did not require the usual amount of food to maintain the balance among activity, food and insulin. In addition, although everything was pushed forward on weekend days (for example, meals were later than on school days), most participants continued to rise at 9:30 AM to give their insulin, as they believed there was no way around this scheduling. Sam did not maintain this schedule and he found that there was a price to pay in that his blood sugars were "all over the place", unpredictably high or low, but never within a normal range. So, science was often intertwined with the art of developing personal and unique guidelines.

Several participants described personal guidelines around food. For example, Ivan shared how he worked candy into his meal plan and Hayley explained the limits she imposed on food intake even though she had given up carbohydrate counting. Essentially, personal guidelines were sometimes used in conjunction with scientific knowledge and they sometimes replaced it. Generally, the scientific way was the first step. However,

scientific knowledge was seldom enough on its own, as it did not allow for the context in which adolescents made decisions. Consequently, adolescents added to, modified, or replaced the scientific knowledge that formed the basis of their decisions. For example, in order to prevent hypoglycemia adolescents usually developed guidelines for activities such as driving. Some of them checked blood sugar levels prior to getting in the car, others ensured that they had eaten a meal prior to driving, or perhaps ensured that the meal was larger than usual. Adolescents sometimes figured out the guidelines that worked for them even though they were not strictly within the scientific recommendations. If they worked and there were no untoward consequences, then adolescents continued to trust their personal and unique guidelines. In the following excerpt, Samantha illustrated her use of scientific knowledge to guide her decisions around driving:

So I just keep like juice boxes and I always have my purse with me and its got tons of food in there so I always, and I don't drive like if I know my blood sugar's low or yeah, I just, I'm really careful like when I'm driving and stuff, sometimes I do [extra blood sugar checking]. Yeah, but usually I go out like right after dinner....Yeah, I do that too [have a big breakfast] just make sure that I eat enough cause it's better to be on the safe side.

Yet, in other situations, Samantha explained that she often treated episodes of hypoglycemia with a relatively simple sugar and did not follow up with a protein although scientific guidelines would suggest that it is important to do so. She explained, "I have a granola bar and usually that's about it – if I'm out like somewhere I just eat a granola bar. For I don't really carry a peanut butter sandwich around with me, they stink." And so, following up with a long-acting protein food, the usual recommendation, faded into the background as Samantha discovered that it was not always necessary to follow the relatively rigid scientific principles in order to prevent hypoglycemia and maintain safety. In a different context such as during an episode of nocturnal

hypoglycemia, Samantha's response was different. This may have been, in part, because her Mom often looked after her during her fairly frequent episodes of nocturnal hypoglycemia and her Mom did indeed follow up the simple sugar with a protein. It may also have been due to the fact that Samantha noticed that she would awaken again if she did not eat enough to see her through the remainder of the night, whereas she had no such symptoms during the day. Essentially, her body signals differed depending on the context and she tended to base her personal guidelines on her body signals rather than the scientific rules of diabetes management.

Just as there were a set of scientific principles that guided participants' decision making, adolescents developed some rules or limits within the context of creating and using personal guidelines. Hayley explained that she no longer used carbohydrate counting. In fact, she probably could not even remember how to use it but she now just "kind of knows" and would base the amount of pizza at lunch on "probably just how hungry I was actually, but I wouldn't have three or four [slices]" so there were personal limits that guided her decision making. There were also times when participants had to develop their own personal guidelines based on their experiences. Sam confirmed this, saying:

So, if I'm high then, if I waited a couple of hours then I will go low just because I'll peak, and then drop. ... it has happened quite a bit in the past where I've just been high and then, like ignored a snack and like, I rightfully ignored a snack because I didn't take insulin or whatever but like, that food would have just made me higher. But the thing is that two hours later I was pretty badly low\_because, not just because I didn't eat the snack but because I had – I was high and then I went low. Or sometimes I'd even eat a snack and I'd go higher but then I'd drop.... I don't think it depends on time even, it just like where you're at in your high.

And when asked how he works with the above, he clarified, saying, "I think I'd take insulin and then eat a snack, that way the insulin takes care of the current high,

brings me down to normal blood sugar and then I have a snack." Essentially, science's shortcomings forced Sam to develop his own management strategies. Like some other participants, Sam found that limitations of this kind were often catalysts for developing unique and personal guidelines.

In summary, participants developed unique and personal guidelines in order to attend to the uniqueness and context of their lives. Similar to scientific guidelines, personal guidelines had limits and "rules." Adolescents used personal guidelines to either complement or to replace science. Often, personal guidelines were given preference over scientific ones, particularly if there were no untoward consequences in doing so. Sometimes, participants developed personal guidelines that were based on body signals rather than the scientific rules of diabetes management.

### Learning from Experience

*"Everything's kind of like it's a new day, you're going to have to deal with new things and every day's different but you also have to look at the similarities."*  
*(Sam)*

Generally, participants considered past experiences as a means of helping them to make decisions and they planned on using ongoing experiences as a means of making future decisions. Frequently, blood sugars within a generally acceptable range were used as parameters for "good" decisions. Past experience with the situation was a useful tool to use when trying to figure out what to do. Sometimes adolescents were so used to making these kinds of decisions that they appeared to be automatic and subconscious. However, from their descriptions it is clear that they were implicitly based on this learning from past experience. Sam explained:

Well, every day is kind of different but I will – I will like, think about it, like 'Yeah, like two weeks ago I did this and I had too much insulin and I ended up low, so maybe I should watch out this time', or I'll be like 'Okay, last time I went biking I came back down I had a "slurpee" and then I was really high because I

obviously didn't bike as much as I thought I had' or like, I wasn't physically active enough that will – that will have worked it off, right? So umm, I kind of look at everything and just – base it on like what's happening today and what has happened, how everything's working and, cause everything, everything's kind of, everything's kind of like it's a new day, you're going to have to deal with new things and every day's different but you also have to look at the similarities and, I think it helps to look at stuff in the past you've done and you will, you probably will remember a couple situations where you got really low or you got really high because you're doing something pretty similar or like, even if its like 'Okay, I went biking two weeks ago and this week I'm doing jogging or something', both cases you're doing something that you're doing for three hours straight and its going to be hard on you and maybe you should look at similar situations, kind of on the same day how you worked your insulin, how you worked your food, everything like that.

In new situations, participants often based their decisions on the unfamiliarity of the situation in that they were usually more cautious, tested blood sugars more often, and sometimes maintained blood sugars at a higher than usual level "just in case". There was a certain amount of a trial-and-error approach with decision making in new situations.

Expert decision making required experience in having lived with diabetes and a confidence in one's ability to make a reasonable choice. Previous experience helped adolescents to develop the confidence that was necessary not only to make decisions in familiar settings but also to make decisions in unfamiliar or new situations. Hayley described how she would handle decisions in a new situation:

I'd probably guess [in new situations] and I would take more off [insulin] than not enough off so I, cause I'd rather be, like say, if I was playing a sport and I couldn't get, umm, like food or sugar or something, so then I'd know for next time and then I'd take more off again if it didn't work.

Another participant expanded:

Just be like, just test out the situation, just look at something that's as close as possible to it or relatively similar but not something exactly the same but like, something relatively similar and then just be more careful with things you do that day or be more careful of what you're doing just so you make sure you don't go too high or too low, If it was something completely different then I would probably umm, test more often, maybe like 4 times a day instead of 3, like I'd add another one in just to see how, just to see how it's affected, that kind of thing.

In summary, participants used past experience to make decisions around similar situations and, in the context of new situations, they sometimes tended to be more cautious and to maintain blood sugar levels at a higher than optimal level. In addition, past experience tended to give participants the confidence to trust their decision making not only in similar situations but also in new ones.

The art of everyday decision making was the second major theme that I identified in the findings of this study. This theme relied somewhat on the first major theme of science. Although participants based many of their everyday decisions on science, they recognized that science was limited in its usefulness in the context of living with a chronic illness. Sometimes, the limitations of science were a catalyst for adolescents to develop a way of living with a chronic illness on a daily basis. This “way” of living with and managing diabetes constituted the art of everyday decision making.

I identified a number of sub-themes within the art of everyday decision making: Responding to Body Signals; Comfort with Highs and Lows; Developing Unique and Personal Guidelines; and Learning from Experience. These sub-themes were embedded in the context and complexity of participants’ lives. They encompassed the uniqueness of their lives and their particular ways of applying the science to their everyday management. Essentially, the art of everyday decision making was grounded in individual ways of responding to, and comfort with, body signals, individual ways of developing personal guidelines, and individual ways of learning from experience. Attending to and acknowledging these individual “ways of living with diabetes,” as well as identifying and interpreting similarities between and among participants’ stories, enabled me to recognize and acknowledge the essence of the art of everyday decision making; namely, the social context of living with a chronic illness

### The Art and Science in a Social Context

As data analysis progressed, it became clear that not only did science fail to account for the context of adolescents' lives; the art failed to account for the social context of their lives as well. As I listened to participants' stories I came to understand that both the art and the science of everyday decision making were embedded in the social context of adolescents' lives. In fact, as I began my analysis, it was adolescents' relationships with others that captured my attention and was the first theme that I felt confident about naming as an actual theme. While relationships with others were an important component of the social context of adolescents' lives, it did not fully capture my interpretation of the findings. Therefore, over time, this theme of relationships with others became the social context of everyday decision making. In addition to the art and science of decision making, the third and final theme was the art and science in a social context.

### Adolescent Culture

Adolescents, as a social group, lead very busy lives involving school, work, sports, exercise, and social activities. The lifestyles of the adolescents in this study paralleled those of adolescents without diabetes. Likewise, the focus of the lives of adolescents with and without diabetes was also comparable in that their friendships, social activities, interests, sports, families, school, and work (not necessarily but quite possibly in that order) were of paramount importance. Yet, the adolescents in this study had to somehow "fit" diabetes into these extraordinarily busy and complex lives and, in order to have been nominated for this study, not only had to fit diabetes into their lives, but to do so with expertise. And they managed to do just that. They slipped in a little decision here and another modification there and described doing so with a casualness

that could very easily deceive unless one was on the alert for the subtleties of how expertise in decision making was enacted.

Diabetes decisions were constantly interwoven with non-diabetes decisions. Adolescents modified their lives by making decisions that allowed them to get on with living life as adolescents. They did what was necessary with as little disruption as possible and, having made the necessary decisions and performed the necessary tasks, they continued to involve themselves in one of the most important aspects of adolescent culture -- namely, social interaction. As Sam noted:

Sometimes I have to like schedule my life around the diabetes kind of thing, right? But most of the time I just – I just kind of work with what I'm doing and with my diabetes– like if I want to go out for dinner or something I'd take my insulin with me but umm, yeah, so far like – umm – yeah, I generally just work my diabetes around my life.

All of the adolescents in this study were diagnosed prior to adolescence and, because of the complexity of their lives, some participants believed that being diagnosed in adolescence would be more difficult than being diagnosed earlier in life. One participant explained:

Basically um, I guess probably it was easier to set up a routine when I was younger....it was like my life was a lot more planned out like day-to-day what I'd be doing, so ah when you're a kid you're not going to be like going out, staying at friend's houses until 1:00 in the morning and stuff like that, so its a lot more probably relaxed life so it's kind of different than it is now but, um, it was more kind of set to what all the doctors and everything tell you when you first leave the hospital like you're doing everything exactly the way you're supposed to, but not like now its slightly different.

Another participant expanded on this notion of the challenges perceived in having diabetes diagnosed in adolescence as opposed to “growing up” with it. This participant explained:

If you're having a lifestyle and then that [diabetes] gets introduced you'll have to change a lot but with me I've had my lifestyle kind of changing and everything's been changing and my diabetes has been able to change with that so, since I've

had it awhile, when my lifestyle's changed I've been able to bring it along and adapt with it so its not been that big a problem.

Nevertheless, even though participants perceived that it was easier to have been diagnosed as children than it would be as adolescents, they recognized that the issues specific to adolescence were challenging and complex regardless of the time of diagnosis. For example, adolescents identified engagement in high-risk behaviors as an adolescent-specific issue. As one participant noted, "People my age do stupid things..." Interestingly, in the interviews, the adolescents in this study tended to minimize the extent to which they participated in such behaviors. In contrast, several high-risk behaviors were openly discussed and acknowledged during the focus group session. For example, during the individual interview, when I asked one participant if smoking or alcohol were issues for her, she replied "Not really" and I interpreted this to mean that she neither smoked nor drank alcohol. Yet, she openly shared her experience with alcohol during the focus group session. This may have been due to the way I asked questions about high-risk behaviors during individual interviews ("Is it an issue for you?" rather than "Do you drink alcohol?") or it may have resulted from the different contexts of data collection methods. Furthermore, while other participants admitted during individual interviews that they drank alcohol, their alcohol-related stories during the focus-group sessions were more specific, as individual participants' comments tended to invite others to respond. Finally, some participants denied that they drank alcohol and did not engage in the alcohol-related discussion during the focus group session, presumably because they did not drink alcohol.

There were occasions when some adolescents' knowledge about alcohol was incorrect. For example, two adolescents thought that alcohol caused hyperglycemia. However, on the whole, it was reassuring to discover that alcohol related decisions were

usually made within the context of safety and advice from health care professionals thus illustrating health care professionals' attention to sharing scientific knowledge as it relates to alcohol, in addition to their recognition of alcohol as part of adolescent culture. One participant explained, "Yeah, the [Health Care Professionals] talked to me about it before – just like not to drink things that have lots of sugar in it or anything. And if I'm drinking just make sure I'm eating too." Health care professionals' acknowledgement of, and teaching about, high-risk behaviors such as alcohol use enabled adolescents to engage in such activities in a way that facilitated their safety. One participant supported this, saying:

Yeah. It [alcohol] is an issue cause, like, there's a lot of problems that could end up happening like, if I threw up or I passed out, that kind of thing, so basically what I have to do is eat starches while I drink and that way, that way my blood sugar will stay up as well and I won't have as big a chance of throwing up so... as long as I keep food down, as long as I made sure I test and make sure I'm not low, yeah, its not a problem.

In summary, adolescent culture framed the lives of participants in this study. Their lives paralleled the lives of adolescents without chronic illness in that their lives centered around social interactions, friends, families, school, employment, and activities. In addition, they made decisions about high-risk behaviors and this was often in the context of advice from health care professionals. Essentially, participants positioned diabetes in their lives in such a way as to minimize its visibility while, at the same time, attending to its importance by making decisions that were compatible with both adolescent culture and their scientific and personal guidelines.

#### Privacy/Invisibility

Some participants, particularly the females, described issues with privacy. Not looking different allowed adolescents to maintain their privacy and to place diabetes in the private rather than the public or social arena. This invisibility then allowed

adolescents to have control, to a certain extent, over issues such as diabetes status disclosure. Samantha believed that not looking different meant that diabetes did not curtail what she could do socially. She explained, “Like not being able to go out with your friends or something – like you can still have a normal life just like anyone else. You can do everything anyone else can. You don’t look different or anything.” In addition, engaging in high-risk behaviors such as alcohol use allowed adolescents to make choices that maintained their privacy, enhanced their invisibility, and allowed them to be “not different”.

Furthermore, in order to protect their privacy and maintain their invisibility, participants made decisions that enabled them to carry out necessary self-care unobserved. Their concern was with strangers rather than with friends. There were reasons for this; namely, they were worried about the responses of others. Some participants believed that others would not want to see them carrying out procedures such as injections; others worried that people might think they were involved in illegal drug taking; and others wanted to keep diabetes in the background and place the focus on the social activity that was happening at that time. As a way of protecting their privacy and maintaining a social focus rather than an illness focus, female adolescents chose to do blood sugar checking and insulin injections in public washrooms even though these places are neither particularly user-friendly nor hygienic, so that others, friends as well as strangers, were not privy to the everyday responsibilities and tasks of diabetes management. One female participant agreed, saying, “I don’t want people to see me do it [give insulin or do a blood sugar]. I don’t want them to think I’m doing heroin or something. And I just feel uncomfortable if people don’t know [I have diabetes].” Interestingly, male adolescents’ responses differed, as the following example illustrates,

"I don't have a problem doing it in front of people. I think it's kind of cool doing it in front of people cause people always get freaked by it."

The decision to inform others of their diabetes was a choice that adolescents liked to make based on the appropriateness and the necessity of disclosure. Generally, friends were well aware of its existence because of the length of friendships dating back to the period of initial diagnosis. In the context of new personal relationships, one participant believed that it was better to disclose from the outset whereas another thought it prudent to wait and see if the relationship developed before disclosing such details. Adolescents described the ways they had of informing others. For example, they "slipped it in" rather than coming out and saying that they had diabetes. As Roger explained, "I don't go to them and say 'I'm diabetic' I would more 'Oh I've got to do my insulin' or something like that. So, I make it obvious." Others, such as Samantha, would just tell people, but she was selective in whom she told. Several participants believed that some adults in their lives needed to know, for example particular teachers or coaches. One participant verified this, saying, "Well, in most classes you aren't allowed to eat in the class. Umm, well, if I have to tell somebody like the teacher, or if I'm with a group of friends I just say I have to slow down for a little bit, my blood sugar's low."

Sometimes, mothers told coaches and made decisions around illness disclosure that adolescents deemed inappropriate. When asked about her Mom's habit of disclosing her diabetes, Hayley explained:

Well, I can understand her point of view of why she would want to do that. But I'd almost want her not to because I don't want – like I don't want people to have to pay special – special attention to me or think I'm any different. Because I don't feel I'm any different – like I don't think I'm any different at all. I'm just like anyone else – I don't – I can understand why it would be good for them to know; but I'd rather them not to know almost so just so I can like do my own thing and not have to – like – I don't know – or not have them worry. I probably wouldn't

tell anyone unless I was friend to someone – like all my friends know – like I wouldn't mind telling people like ‘oh’, it’s like ‘oh, do you want a Coke’ and if it wasn’t that it I’d be like ‘oh no, I can’t.’ I’d tell them but – like if I was in a class, I wouldn’t walk up to the teacher and like ‘I’m Hayley – I’m diabetic.’

On occasion, disclosure resulted in negative consequences, as Alyssa’s example clearly illustrates. When Alyssa was diagnosed her Mom wanted her to cut back a little bit with her dancing lessons. As a result, the teacher put her in a lower class. Alyssa quit dancing as a result of this interaction and explained:

I truly don’t believe that it was a way to help – of my teacher helping me cut back. I think she thought I wasn’t exactly good enough for that just because I had diabetes I wouldn’t be able to perform as well as I did before. So, yeah that’s about it – you know she would – she would kind of – like when she talked to my Mom about my diabetes she’d – she’d almost seem like it was a disability – like it was – I don’t know how to explain it but it was more of a disability than I could live with it or something.

When asked how that made her feel, Alyssa responded,

Oh! Horrible! I couldn’t stand it – it like – like I was a 10-year old and, you know I just had this – this thing just like dropped on me about diabetes and just having my teacher just think I’m basically DIRT! Like it just made me so upset. Well, she [Mom] talked to her about it and you know she said that ‘Alyssa can just perform just as good as she did before’ but it really didn’t seem to make a difference.

This example graphically illustrates, in the context of illness-disclosure decisions, the potential of paradoxical consequences; namely, safety and stigma. One of the primary reasons that adolescents disclosed their health status was to maintain safety. Specifically, participants believed that it was important for friends and significant adults to know that they had diabetes, not only so that they understood adolescents’ eating habits, but also to be on hand should there be an episode of hypoglycemia. Yet, Alyssa’s example illustrates the potential “risks” of disclosure. Essentially, adolescents had to make a choice; were the safety issues important enough to risk potential stigma? -- or, was invisibility

important enough to risk safety? Participants' decisions were varied and based on the context of the particular situation.

In summary, facilitating privacy and maintaining invisibility were important to the participants in this study. In particular, the female participants deemed these issues to be significant and they devised ways of ensuring that their diabetes remained invisible, especially to strangers for whom there was no valid reason for disclosure. On occasion, participants disagreed with their mothers' decisions to disclose their health status. In one case, disclosure resulted in a participant's extreme discomfort and feelings of stigma. Finally, adolescents were willing to share their health status when they deemed it appropriate, particularly to maintain safety.

### Relationships

Adolescents' stories of everyday decision making were grounded in the many relationships in which they were immersed. These relationships were both personal and illness-focused. In a sense, illness-focused relationships were aligned with the science of everyday decision making whereas personal relationships were more closely aligned with the art. Participants' lives were strongly relational therefore it was not surprising that much of their decision making occurred in the context of relationships, both personal and illness-focused.

### Illness-Focus Relationships

Participants differed from their adolescent counterparts without diabetes in that they had relationships with individuals and groups where the primary reason for and focus of the relationship was diabetes. For the most part, these relationships were in the background of adolescents' lives. There were two types of relationships in this category: relationships with health care professionals and relationships with others with diabetes.

Overall, participants' experiences with the health care system and with health care professionals appeared to be quite positive. All of the participants attending a pediatric health care facility reported relationships with health care professionals in which they felt respected and supported. Nevertheless, adolescents saw their team so infrequently that it was difficult for them to define what they shared as a relationship, thus placing such interactions in the background of participants' lives. One participant agreed, saying, "They're really nice. I only see them twice a year so I don't really have much of a relationship but when I go in they're always friendly and really nice."

Although adolescents appreciated both the respectful nature of the interactions that they had with their health care professionals and the fact that health care professionals considered the context of adolescents' lives when negotiating management strategies, they were cautious when considering implementation of such strategies. For example, when asked how she felt about a recommendation that her health care professional had made, Samantha replied, "Umm, I guess it's a good idea. I don't know, I'll have to see." Similarly, Sam agreed that his response to health care professionals' recommendations was a "wait and see how it works" approach. He explained:

Umm, I kind of look at how things are going first of all and then I'll listen to what they have to say. I'm not going to be like 'No, I don't want to do that!' but I'll listen to what they have to say and depending if I think it will work for me, I'll either use it or not, like I'll certainly consider it, I'll try what they're saying but, umm, if it means a lot of, if it means a lot of adjusting of my schedule and everything, umm, I probably won't change it, change that much but I'm open to ideas if they have, if they have some ideas of how I can change things that will help me work with my diabetes and have it work to the better than I'll listen to it, try it out, hey! It might work you never know and if it does, it will great so, yeah, I listen to their suggestions.

Most adolescents were nominated by one of their actual caregivers and thus considered to have expertise. Therefore, one might assume that these particular health care professionals valued collaborative relationships with their clients and trusted and

respected their judgement. Roger, on the other hand, was nominated by a health care professional not directly involved in his care and he believed that his sole health care provider, a physician, would not have nominated him as having expertise. When discussing issues around driving, Roger described a potentially conflictive issue of power between himself and his physician. He clarified:

My understanding was that my doctor does have the ability to stop me from getting my license. That actually worried me and you know – he said I think – he sort of made an indirect threat to not let me get my license if I wasn't a very good diabetic by saying he has the power to but I might have taken it wrong. I mean I was kind of nervous about getting the license at the time so I probably did take it wrong.

During individual interviews several adolescents described positive and supportive relationships with health care professionals. Interestingly, the dynamics and context of the focus group generated a discussion around less supportive responses to and by health care professionals. One of the issues that participants described involved the expectations that health care professionals had of adolescents around food management. Adolescents believed that these expectations were unrealistic and unmanageable yet they seldom challenged their health care professionals on these expectations. Instead, they chose to say nothing, continued to make decisions based on what worked for them, and, as a result, they sometimes felt guilty and health care professionals were, presumably, unaware of their feelings about these expectations and issues. One participant explained:

Foods and diets! I found that health care professionals are really structured on diets; they have this incredible program and stuff! Like pages and pages of diets and stuff, Yeah – couple of dietitians it's like 'oh!' it's so strict like they expect you, well, they don't expect you but I don't know, I don't – like, feel overwhelmed by how they talk about it you know, Well, just because it's like, so do you want to change your 1 starch and your 1 veggie whatever, it's like, well, I don't know, like I don't always have that in the morning. I change my diet, if I followed an exact routine, it's really boring.

In addition, participants described negative but non-verbal responses of health care professionals that made them feel responsible for non-optimal or high blood sugars, a conclusion with which adolescents tended to agree. Again, participants never challenged health care professionals on these issues. One participant confirmed this, saying, "Oh no, they never say it – You just feel it. Like there just like a sense in the room, it's like if I'm high I'm like I don't know, bad or something, Yeah, you feel responsible....Yeah, Well, you are responsible."

None of the participants were interested in the idea of illness-specific support groups. Some had tried them, most had not, but all agreed that placing diabetes as the focus of a relationship would not appeal to them. Allowing diabetes to be the predominant focus in their lives was unappealing to participants and they tended to avoid forming relationships that were based on their chronic illness. Some adolescents explained that family and friends were all the support that they needed. One participant confirmed this, saying:

I went to a couple of meeting kind of things but it was pretty boring so, yeah it was like - I was just like, I kind of figured from the view 'why do I need support from this?' I'm dealing with it fine like, my family's dealing with it fine and I'm not having any big problems and it's not that big a deal; I'm not going to let it affect my life so I can deal with it, so just see how it works and, I don't know, like it's just kind of one of those things where if I had the choice between just sitting at home and talking to my parents for, like an hour about choices that I should or shouldn't be making or sitting with a bunch of people, that I think sitting with my parents would be better or sitting with my doctor would be better because they know more - they know more about me specifically and they do know that - they do know what my tolerance to different things will be - what my tolerance to doing more or less - or what my tolerance to ingesting that much or that kind of thing. Like the support group seems to be a thing where you go to talk about all the problems that you're having and I'm not having any problems so I don't really care for it....another thing I don't like about it is like, you should be getting friends with other people who are diabetic when 'why do I care?' - I don't care if my friends are diabetic or not.

In summary, illness-focused relationships were comprised of those with health care professionals and those with others with diabetes. All the participants in this study maintained relationships with health care professionals and, with one exception, all continued a relationship with a team of diabetes specialists. In contrast, none of the participants were interested in developing relationships with others with diabetes. For the most part, illness-focused relationships, particularly those with health care professionals, were valued but were in the background of adolescents' lives

### Personal Relationships

While associations with health care professionals took a back seat in the lives of adolescents, this was not so of their personal relationships. Adolescents' lives were embedded in personal relationships and families and friends featured frequently in their stories of everyday decision making. Relationships with families were usually, but not always, supportive. Ordinarily, the support that adolescents received from family and friends allowed them to position diabetes in the background in a way that facilitated healthy management together with a primary focus on living life as an adolescent.

The notion that family "support" was not always helpful was highlighted during the focus group when group dynamics facilitated a lively discussion about the "overprotective" behaviors of parents. Yet, adolescents understood that parents' concern was sincere and was not designed to irritate them. Interestingly, friends appeared to facilitate adolescents' minimization of their diabetes (placing it in the background) whereas families, particularly parents, tended to do the opposite (frequently brought it to the foreground) by asking questions about diabetes management and, in so doing, increased its visibility and reminded adolescents about its importance in their lives. Occasionally, parents' intense interest in adolescents' blood sugars resulted in

adolescents feeling guilty. One participant explained, “I hate telling her [Mom] when I’m high – she’s like ‘what did you do? What did you have? Don’t do that’ kind of thing. She wants to make sure I’m doing really well but that’s understandable but I usually know what I’ve done wrong.” Another participant expanded, “It doesn’t bother me – I just feel bad like having to say – I don’t know – I just feel guilty if it’s high cause I know it’s my fault but I know she just always gets really worried and wants everything to be good – I don’t know – feels like I’m letting her down somehow.”

Furthermore, parental attitudes encouraged some participants to withhold or, indeed, to fabricate blood sugar results. One participant verified this, saying:

I know my blood sugar is going to be high, I’d tell my mom that I’ll do my blood sugar by myself and I just won’t tell her (laughter) – sometimes I take it and I’ll like test with the testing thing. [doing so would ensure that an “acceptable” blood sugar value would be recorded on the meter] It’s not very good though.

In addition, family members’ comments on food choices angered and irritated adolescents. When asked if people saying, ‘Should you be eating that?’ bothered her, Alyssa responded, “Yeah – it does bother me cause sometimes I’ll be out with my cousin and she’ll say, ‘Should you be having that?’ I’ll say, ‘My blood sugar’s low’ and she says, ‘Are you just saying that?’ Nevertheless, participants did understand that parents’ “interference” emanated from a place of caring.

At times, adolescents talked about “bad” decisions and what they did “wrong.” These decisions were generally related to food choices and, presumably, were based on the knowledge base that they had since diagnosis. Ivan explained, “KFC is really bad....one of the worse because there’s 10 fat choices in one drumstick.” And Hayley equated “bad” choices with high-sugar foods, She explained, “So many things have sugar in it. And I’ve made bad decisions before and like I’ve had a Slushy or something... well... no, not, not usually cause that’s really bad to have but I’ve had cinnamon buns

before and I've got home and I'm a bit high and that's okay though." In addition, the notion of "bad" choices was sometimes shared by others as the following excerpt illustrates. Hayley explained:

My boyfriend, he knows everything – like he sees something I shouldn't eat he rips it away and throws it in the garbage or something... like he doesn't let me eat anything bad.... he's healthier than I am so that's why he doesn't want me to eat anything bad....most of my friends don't really like – they're all on diets! So they really don't like to eat bad things too.

Notably, many of the stories of parental support centered on help with the somewhat tedious tasks of diabetes management such as drawing up early-morning insulin. The actual decision making process was usually independent especially among the older adolescents, and parents were often perceived as consultants and used in a collaborative way to check decisions already made. The younger adolescents were much more dependent on parents to make decisions, particularly in the realm of insulin dosage and adjustment. Decision making around food choices and activity were frequently made independently even in younger adolescents.

Interestingly, and perhaps not surprisingly given the social context of many mothers' lives, mothers were consistently named as the parent most directly involved in the helping role and decision making process. Adolescents talked about supportive parents but, when questioned, usually described mothers as the primary caregivers. Female participants seldom mentioned fathers as being directly involved in diabetes care. In contrast, male adolescents did refer to fathers' direct support.

Participants' stories of mothers' support were rather impressive and I was exposed to a strong sense of mothers' support during my visits to adolescents' homes. The mothers with whom I spoke were enthusiastically supportive of their adolescents' inclusion in the study and spoke warmly about their child's self-care management.

Participants appeared to implicitly expect support from mothers. Furthermore, they accepted it, appreciated it, and some of them actively sought it. One participant explained, "My Mom is the most supportive and she's the big one – she gets my insulin most of the time and she's the one with the food but everyone else is really supportive and really nice – they're not negative in any way and they're really nice." Samantha expanded:

Okay, I woke up this morning with low blood sugar at about 1:00 so I went and got my Mom and she went downstairs and got me a snack because I don't like going down in the morning because it's too cold and also she'd rather get me my snack than have me to down by myself....I babysat until 4:00 this morning so my Mom came up and did my insulin for me in bed so I could sleep in an extra 45 minutes. Cause I was very tired.

Sam was the only one who alluded to the notion that parents also were affected by the chronic illness. Families' support was sometime hidden, as Samantha's account, given laughingly, of her family's attempts to support her by not eating "forbidden" foods in front of her illustrates. She explained, "Because they know – they wait until I go out, because I go out most of the time so they do that – then I'll come home and I'll see like the wrappers and stuff in the garbage can." Interestingly, when Samantha and her Mom disagreed over diabetes management, specifically over whether to increase food or reduce insulin, Samantha's mother respected her daughter's decision and their opposing views on management led Samantha to be more independent in her decision making. She explained:

I make my own decisions about that. That's how my mom feels, my dad feels; she usually doesn't do that; she just thinks I should mostly cut back on what I eat or something instead of having insulin so I usually just do it myself. Yeah, she likes to decrease the food, and I like to increase the insulin – I think it's just – she probably just thinks it's easier but I just would rather have more. Like, more insulin so I cannot have to cut back – because – I mean – some time during the day – I would rather like to have to eat if my blood sugar was low than have to worry about it being high. It's just easier that way.

In summary, relationships with families were generally supportive and facilitative of adolescents' everyday decision making. Participants expected, accepted, and sometimes sought support. While the females spoke almost exclusively about maternal support, the males alluded to their fathers as being supportive in addition to their mothers. Parents were often used as consultants rather than actual decision-makers and, from one participant's perspective in the context of disagreement, her parent often conceded to her decision, thus illustrating, in my view, parents' respect for adolescents' expertise. The younger adolescents in the study were more apt to use parents as decision-makers, particularly in the realm of insulin dosage and adjustment. Although families were deemed to be generally supportive, there were times when adolescents perceived their parents as being somewhat overprotective thus increasing the visibility of diabetes in the adolescents' lives. Furthermore, such parental responses resulted in participants' unwillingness to share diabetes-specific information and, on occasion, to actually fabricate blood sugar values.

Although adolescents were irritated when family members commented on food choices the same was not true when friends did so. Friends' comments were perceived as facetious and were taken neither offensively nor too seriously by participants. As one participant explained, "Well, I really don't care that much about what my friends say cause they really don't know that much – my parents or my sister get on my case – it really annoys me – it really bugs me sometimes." In the context of comments about food choices, friends appeared to respect adolescents' expertise in a way that families did not. One participant confirmed this, saying:

You know going out with my cousins or something cause I usually go out with my cousins a lot and they're always concerned with my diabetes. So if I go out for lunch with them or something it would be 'oh, oh, oh should you be having that! Shouldn't you have some things with a bit less in fat or a little bit less of this on

your steak?' 'It's fine – it's okay' but yeah, it's a lot different with – it's a lot different from when my friends say it cause I think they feel that umm like if I say – like it's okay – it's okay that I'm having it – they just drop it, like right away – like they don't mind. It's like they know ....that I have the diabetes – like I'm sort of like the expert so I know what I should be doing and they just leave me alone after that. It's like 'yeah, just leave me alone.'

Friends were perceived as being very caring, particularly from female participants' perspectives. In addition to being generally supportive, friends also supported adolescents' decision making in terms of lifestyle choices. With the exception of Roger, adolescents' friends were actively involved in sports/fitness/exercise activities thus rendering such a lifestyle as the norm. In addition, Hayley's friends made both lifestyle and everyday choices that she perceived as supporting her decision making. She shared her perspective, saying, " Well, most of my friends don't really like – they're all on diets! So they really don't like to eat bad things too but like they're always be 'Oh, we'll just wait and go to Subway or something' or like they'll do things for me."

Although participants were happy that their friends looked out for them and were aware of their diabetes, they made it very clear that they did not want their friends' food choices to be affected by their diabetes. Specifically, they did not want friends to base their own food choices on what they, as individuals with diabetes, could or could not eat. In addition, friends' food choices did not usually influence participants' food choices, as participants tended to make their food choices based on reasons other than craving what their friends were having. If they decided that they did indeed want the same they tended to be moderate in their portions and share " just a little bit of theirs."

As I tried to understand the impact of friends' food choices on participants, it became apparent that participants were less concerned with the impact of friends' choices on themselves and more concerned with the possibility that their diabetes-management decisions might have a negative impact on their friends' food choices. The reluctance to

allow their diabetes to have a potentially negative impact on their friends' food choices exemplifies participants' caring attitude toward their friends, their reluctance to allow their illness to intrude on their friends' lives, a desire to maintain a degree of invisibility, and not wanting to be different. They were emphatic in that they didn't want their friends to be affected in any way. One participant verified this, saying, "I don't want to prevent anyone from doing something they want to do just because I'm there, right? So I'm pretty flexible like that – I'm not going to cause problems for other people just because I'm there."

In summary, relationships with friends were supportive and the females also perceived friends to be caringly so. In addition, stories of friends' support featured more predominately in female participants' accounts than in those of their male counterparts. Adolescents understood friends' support as including lifestyle choices, a willingness to compromise in order to accommodate the options available to the adolescent with diabetes, and a caring and sometimes protective attitude. Interestingly, participants were reluctant to allow diabetes to have an impact on their friends' lives, specifically, friends' food choices.

Overall, personal relationships with others were very visible in participants' accounts of their lives. From their descriptions, it seemed apparent that adolescents considered the relationships they had with others to feature importantly in their decision making around diabetes. Support from families and friends was a crucial component of adolescents' everyday decision making. Judgements about food choices were perceived as unsupportive and interfering when received from family members, yet, similar comments from friends were received much more favorably. This phenomenon of accepting judgements from friends while rejecting them from families is, I believe, not

uncommon with adolescents in general. Even though adolescents perceived parental responses and comments as interference, they understood that parents were simply being caring and protective. Furthermore, for the most part, parental support was positive and allowed adolescents to manage their diabetes care both independently and interdependently.

### **Summary of the Findings**

Adolescents in this study, with one exception, were very positive and pragmatic about their chronic illness. Although they lamented certain restrictions (most notably dietary ones), for the most part, they neither dwelled on their situation nor considered themselves unfortunate compared to their peers. Their everyday decisions were based on the reality of having diabetes and their pragmatism enabled them to place diabetes in the background by doing what had to be done and getting on with life as adolescents. The findings from this study generated themes that represent everyday decision making for adolescents with expertise in diabetes management. My interpretations of the data were that everyday decision making is both an art and a science and is played out in the context of adolescents' social lives. The art and the science of everyday decision making flows well semantically and I chose to use this title order even though it was evident from participants' accounts that the art followed the science. Not only did the art follow the science, it relied on it, often complemented it, and sometimes replaced it. The science of everyday decision making provided participants with guidelines on which to base many of their decisions. For the most part, these scientific principles were somewhat general and acontextual, and were, therefore, of crucial but limited value in terms of adolescents' uniqueness and individuality. In order to address this gap and to "contextualize" life with diabetes, adolescents practiced what I interpreted as the art of everyday decision making.

This art was grounded in participants' individuality and enabled adolescents to "fit" diabetes into their everyday lives.

The art and the science of everyday decision making were often complementary to one another and, as previously discussed, the art compensated for the science's lack of attention to the context of adolescents' lives. Nevertheless, the art did not fully represent the entire context of participants' lives; namely, the social context. Therefore, the third theme of the art and science in a social context was a crucial one to include in order to fully represent the stories that adolescents shared.

Both the art and the science of everyday decision making were enacted in the social context of adolescents' lives. The social context was grounded in adolescents' relationships, both personal and illness-focused. In addition to relationships, adolescents' lives were embedded in issues of significant importance in the context of social living; namely, privacy and adolescent culture. In essence, the social context of participants' lives was grounded in a positive climate that facilitated their ability to enact the art and science of everyday decision making.

### **Conclusion**

In conclusion, there were some interesting findings related to the research process. In addition, the data from this qualitative study resulted in findings about how adolescents with expertise make everyday decisions. In essence, this chapter represents my interpretations of adolescents' stories. I have attempted to separate individuals' perceptions from common patterns and, when possible, I have tried to articulate such distinctions clearly. At times, individuals' accounts represented a noted pattern whereas, at other times, individual participants' accounts represented a particular and unique perspective. My commitment to attending to both the particular and the common

perspectives was influenced by my choice of methodology and allowed me to stay “true to the data”.

## CHAPTER FIVE: DISCUSSION OF THE FINDINGS

In this chapter, I make choices, as I did in my interpretations of adolescents' stories, in how and what to present as particularly interesting and noteworthy. Underlying my choices was my desire to attend to and highlight findings that have special relevance for nursing; specifically, development and extension of knowledge that pertains to practice, education, and research. In particular, I was guided by the commitment that I voiced in Chapter Three to ensure that "my study will or should have significant implications, however small, for nursing practice and ultimately for those individuals for whom we provide care" (p. 14). Further, the decisions that I made were influenced by my understanding of which findings were significant, the similarities and differences of the findings compared to the current body of knowledge, and what I would do differently if I were to consider a similar study in the future. The literature I reviewed in Chapter Two influenced my choice of sample, data collection methods, and data analysis. In addition, the findings from this study directed my reexamination of that literature and guided a new search of unexplored and relevant theoretical and research knowledge. In this chapter, I discuss selected key findings in relation to the current literature thus placing this study in the context of the overall body of knowledge pertaining to adolescents' everyday decision making in type 1 diabetes.

Findings from this study highlighted four contexts in which participants' everyday decision making is both embedded and enacted. These contexts were comprised of individual, gendered, social, and socio-political contexts. Individual contexts included personal characteristics such as attitudes and knowledge. Gendered contexts were significant in the social domain especially in terms of the visibility/invisibility of

diabetes. Much of the social context of everyday decision making centered on relationships with families and friends and the importance of these relationships to both the individual and gendered contexts of everyday decision making will be highlighted. Finally, although relationships with health care professionals were conceptualized as part of the social context in Chapter Four, I came to understand relationships with health care professionals as part of the overall health care system and thus more appropriately positioned in the broader socio-political context.

While relationships with health care professionals were discussed with participants, there were other aspects of the socio-political context that were somewhat invisible throughout participants' stories. Perhaps it would be unrealistic to expect that adolescents might have alluded to such a context, particularly since I did not have the foresight to ask questions that related to, for example, the economical aspects of health care access. However, it would be negligent to consider a discussion of this study's findings without attending to the notion that the participants in this study were, based on their descriptions of how decision making was enacted, somewhat "privileged" in terms of health care access. Specifically, participants had access to the everyday diabetes supplies and equipment that may be a necessary prerequisite for the "expertise in action" inherent in the findings of this study. Attending to this aspect of the socio-political context is particularly timely given the recent changes in diabetes funding allocation in British Columbia. These four contexts represent the main findings from this study and will be the focus of discussion in the first section of this chapter.

Of further interest, and thus warranting discussion, is the notion of "doing" research with adolescents who were nominated as having expertise in self-care

management of their diabetes. The recruitment difficulties that I experienced, the use of a variety of data collection methods, and the nomination-style strategy were significant process issues. In addition, the participant selection procedure resulted in some ambiguities around “participant fit”. Such ambiguities were further complicated by the ambiguity around the definition of expertise.

Given that adolescents in this study were nominated as having expertise in everyday decision making, and regardless of the ambiguity of the definition of expertise, it is reasonable, in my view, to assume that the contexts that were deemed important to participants’ everyday decision making might be linked to expertise. If this is indeed a fair assumption then my deliberations might be a beginning step in understanding expertise in everyday decision making. In the second section of this chapter, I will consider this tentative assumption in addition to a discussion about the research process findings.

### **The Context(s) of Everyday Decision making**

The context(s) in which participants’ everyday decision making occurred were comprised of those in the individual, social, gendered, and socio-political arenas. In the first section of this chapter, I will highlight particular aspects of each context in order to illustrate their importance to the present study.

#### Individual Context

Although there were many unique features to the individual context of adolescents’ lives, there were some interesting similarities that comprised patterns and represent what I prioritized as being important to adolescents’ everyday decision making.

These similarities include adolescents' attitudes, knowledge, and concerns about the future.

### Attitude

Findings from this study indicated that, with one exception, participants perceived themselves as healthy individuals, thus aligning with the notion of health within illness (Lindsey, 1996) and with the findings from a study exploring "exemplars" experience of self-managing type 2 diabetes (Ellison & Rayman, 1998). Interestingly, Roger did not assume a healthy self-perception and viewed health and diabetes as mutually exclusive. Perception of health within the context of a chronic illness may well be an important component of living 'well' with diabetes.

A positive attitude towards diabetes similar to that identified in this study has been described as important by others (Lo, 1999), although some studies with adolescents revealed overall negative attitudes in relation to the experience of having a chronic illness (Kyngas & Barlow, 1995; Woodgate, 1998a). Several researchers have attested to a turning point in adolescents' and adults' lives as being pivotal to a positive change in diabetes management (Christian, D'Auria, & Fox, 1999; Ellison & Rayman, 1998; Hernandez, 1995; 1996; Thorne & Paterson, 2001), although participants in this study did not identify a turning point in their lives.

Findings from this study revealed daily routines to be a crucial part of adolescents' life structure despite the challenges that this sometimes entailed. The importance of such routines is supported in the findings of others (Meldman, 1987). Furthermore, in general, participants were very pragmatic about the routines and the everyday responsibilities associated with self-management. In a sense, their attitude

allowed them to efficiently perform necessary tasks, make decisions, and carry on with their lives. Their pragmatism allowed them to place diabetes management in the background for the most part but also allowed them to move it forward to the foreground when necessary. This finding is somewhat supported by Paterson (2001a) who developed a shifting perspective model of adults living with chronic illness; a model that recognizes that living with a chronic illness involves a process in which an illness-in-the-foreground perspective competes with a wellness-in-the-foreground focus. Paterson maintains that “the major paradox of living in the wellness-in-the-foreground perspective of chronic illness, is that, although the sickness is distant, the management of the disease must be foremost; that is, the illness requires attention in order not to have to pay attention to it” (p. 24). In my view, this captures both the experiences of adolescents in the current study and the complexities of everyday decision making in type 1 diabetes. An illness that requires attention in order not to have to pay attention to it is dependent on a sophisticated level of scientific and experiential knowledge that was evident throughout adolescents’ stories.

All in all, individual attitudes towards having, living with, and managing a chronic illness appear to have a significant influence on the overall positive “integration” of diabetes in adolescents’ lives. The notion of integration is supported by Hernandez (1995; 1996) who developed a theory of integration and Hernandez, Bradish, Wilson Rodger, and Rybansky, (1999) explained that, by paying attention to body signals, individuals integrated diabetes successfully into their lives, thus avoiding it being a primary focus of living.

### Knowledge

Numerous authors attest to the extraordinary demands of diabetes self-management and Rubin (2001) maintains that his son “has to stop what he is doing and deal with (or at least think about) his diabetes at least once every fifteen minutes” (p. 55). That amounts to a significant amount of decision making about diabetes on a daily basis. The findings from this study graphically illustrated the complexities of, and the time required for, everyday decision making. In order to attend to such complexities, adolescents’ diabetes management was dependent on their scientific and experiential knowledge. Findings from Christian, D’Auria, and Fox’s (1999) study with adolescents supported the view that adolescents need both factual and experiential knowledge and, although Coates and Boore (1998) agreed that knowledge is essential for competent self-care, findings from their study with adults revealed that knowledge was not found to have any practical benefit for diabetes management or outcomes. These authors then suggest that health care professionals need to place less emphasis on cognitive knowledge and more emphasis on shifts in behaviors that might foster motivation, decision making and empowerment. While I agree that it is essential to consider these latter concepts, I believe that acquisition and maintenance of knowledge remains crucial to diabetes management and I would also argue that these concepts (motivation, decision making and empowerment) are not devoid of cognitive knowledge as suggested by the above argument.

Nevertheless, of some support to Coates and Boore’s (1998) recommendation are Hernandez’ (1995) findings indicating that health care professionals’ teaching was not the central factor in helping individuals acquire diabetes knowledge; experiential learning

was also crucial. Findings from Meldman's (1987) study revealed that physicians were the health care professionals most frequently referred to as the main source of knowledge regarding self-management. In the current study, participants referred to physicians more frequently than they did nurses and, when questioned about the role of different professionals involved in their care, one participant could not clearly identify the role of the nurse.

For the most part, participants in the current study gained scientific knowledge from health care professionals particularly at the time of diagnosis. Schreiner, Brow, and Phillips (2000) suggest that anticipatory guidance should be used to share knowledge with adolescents. Furthermore, these authors speculate that adolescents, if diagnosed at an early age, might continue to use the knowledge given at the time of diagnosis whereas a refresher course may be timely and relevant. In this way, adolescents could be given an opportunity to explore current scientific thinking, reflect on their knowledge base, and consider ways of incorporating new and/or revised knowledge into their everyday diabetes management.

The limitations of scientific knowledge and the importance of both scientific and experiential knowledge are strongly supported by the findings of the current study. This is important as health care professionals may place significant emphasis on the scientific knowledge that is deemed most relevant to diabetes management. Hernandez (1995), Price (1993), and Thorne and Paterson (2001) agree that scientific knowledge has limitations. Price developed a model of diabetes self-management and her findings revealed that the most useful knowledge, in terms of what worked best for individuals,

may be based on personal reasoning and experience and may not be rooted in the theoretical principles of diabetes.

Personal reasoning is linked to the findings from this study that revealed the importance of knowing body signals. Detecting and trusting body signals developed and improved with experience. Responding appropriately required a finely tuned experiential knowledge that was not grounded in science. This experiential knowledge relied on past experience, the stage of the illness trajectory, the availability of glucometers, and adolescents' confidence in their ability to reliably use body signals. Interestingly, adolescents had to be very discriminating as to what body signals they heeded, what signals they could trust, what signals they needed to check, and what signals they had to ignore. Participants in the current study believed that they were generally accurate when they did check body signals; a finding that is interesting given that Ruggiero, Kairys, Fritz, and Wood (1991) investigated the accuracy of adolescents' blood glucose estimates and found that greater than a third of the estimates were accurate, about a third illustrated harmless errors, and less than a third were imprecise to a clinically pertinent degree.

Several researchers in adults have noted the importance of body signals such as those reported in the current study: body listening, body knowing, body trusting and body checking (Hernandez, 1995; 1996; Hernandez, Bradish, Wilson Rodger, & Rybansky, 1999; Hernandez, Bradish, Spence Laschinger, Wilson Rodger, & Rybansky, 1997; Price, 1993; Thorne & Paterson, 2001), and Price noted that body listening, in conjunction with blood glucose monitoring, was the dominant determinant for diabetes management decisions, an observation that is supported by the findings of the current study.

One of the challenges associated with body signals identified by participants in the current study was the notion of having to ignore certain body signals. For example, sometimes, because of hyperglycemia, participants were unable to eat when they were hungry. Similarly, on occasion, they were forced to eat because of hypoglycemia, despite not being hungry. Kyngas and Hentinen (1995) also noted these specific challenges in their research with adolescents in Finland. This is worth noting as, on the one hand, adolescents are having to finely tune their responses to body signals; on the other hand, they are having to ignore some of the basic human body needs such as eating when hungry, and doing so is bound to entail some frustration, as was pointed out by participants in the current study.

### Worry about the Future

Although adolescents' lives are ordinarily established in the present (Schreiner, Brow, & Phillips, 2000) and people often assume that adolescents are unconcerned about the future, findings from this study revealed that worry about and preparation for the future played a considerable role in adolescents' everyday decision making. Even though some participants were unwilling to make extreme changes to their current lives to prevent future consequences, several participants' everyday decisions were aimed at minimizing the risk of future complications. This finding is not supported by some authors who maintain that the degree to which children or parents' diabetes management is influenced by future complications is unknown (Schilling, Grey, & Knafl, 2002) or that young adults' decision making is not reflective of their worry about long-term complications (Dunning, 1995). However, several authors (Cappelli, Heick, & Feldmann, 1989; Coates & Boore, 1995; Hentinen & Kyngas, 1996; Kyngas & Barlow, 1995;

Kyngas & Hentinen, 1995; Woodgate, 1998a) supported the notion that adolescents and young adults with diabetes do worry about the future. This finding is particularly relevant given that health behaviors developed in adolescence may have a significant impact on consequences in the future (Bennett Murphy, Thompson, & Morris, 1997).

### Gendered Context

While many researchers appear to ignore gender as a potentially significant variable, several researchers have investigated gender as an important aspect of living with a chronic illness (Brink, 1997; Cohn et al., 1997; Faro, 1999; Fitzgerald, Anderson, & Davis, 1995; Hanna & Guthrie, 1999; Hentinen & Kyngas, 1996; La Greca et al., 1995). Thorne, McCormick, and Carty (1997) maintain, "the social experience of living with chronic illness and disability is neither gender nor context neutral" (p. 3). The findings from this study support this view, as gender and context(s) were of significant relevance to adolescents' everyday decision making. I have come to understand that gender may well be invisible unless researchers and health care professionals are committed to making it visible. Thorne, McCormick, and Carty suggest that nurses are well positioned to challenge such invisibility. To be honest, had I not been exposed to Williams's (1999) work, I might not have placed emphasis on gender in the present study.

Findings from Williams's (1999) study influenced my decision to aim for equal gender representation in the small sample in the current study. Williams explored the relations among gender, adolescence, and diabetes management, and gender was found to have a large impact on adolescents' diabetes management. Gender was also associated with mothers' involvement in their adolescents' diabetes management, with the mothers

of sons much more inclined to be involved in their sons' management than the mothers of daughters. Daughters were expected to be more independent in their self-care than were sons. William's findings were not supported by La Greca et al. (1995) whose study exploring support for adolescents with diabetes revealed no gender differences in family support. In addition, findings from the current study contradicted Williams's findings as both the females and the males reported significant support from their parents, particularly their mothers, thus refuting the notion that self-care expectations were greater for females than for males. It is worth noting that William's study took place in the United Kingdom and it is feasible that cultural contexts may have contributed to the different conclusions.

I found some of Williams's (1999) findings to be somewhat worrisome as the notion of sexism within families where adolescents have a chronic illness has social implications. Females were hesitant to ask for support because of the high expectations of parents and Williams speculated that this might result in secret non-adherence. Consequently, females shared feelings of guilt and shame that were not described by males. Given the findings from the current study and the literature that supports the importance of family support to adolescents, Williams's (1999) study is the first, to my knowledge, that has identified such a sexist discrepancy and has, therefore, made an important contribution to our knowledge base in the context of adolescents and chronic illness. I have to admit to having had a degree of bias when I approached this issue in the current study, as I was hopeful that my findings would not support those of Williams. Indeed, I was relieved that they strongly refuted them. There is little doubt that further research in this specific area of adolescent support is necessary.

Findings from the present study revealed that there were some differences between female and male participants. Specifically, the female participants considered issues of privacy and invisibility to be significant and they devised ways of maintaining privacy and preserving invisibility. In addition, while participants perceived friends as being supportive, the female participants perceived them as being 'caringly' so. Also, females described life-style behaviors of friends as supportive. Although male participants did not explicitly articulate such behaviors as supportive, it was evident that they also had friendships with those whose lifestyles were compatible with and supportive of exercise and physical activity. However, it is unclear if male participants perceived such friendships as supportive. Interestingly, findings from La Greca's (1995) study indicated that females noted more support from friends for their diabetes care than did their male counterparts.

Furthermore, participants in the present study indicated that mothers in particular were most supportive and while male participants mentioned fathers' support, the female participants seldom did so. Even though La Greca et al. (1995) did not specifically ask which family members gave support to adolescents, their findings revealed that 59.6% named mothers and 14% named fathers as the supportive family member.

### Social Context

Adolescents' everyday decision making was embedded in the social context of their lives. In particular, their relationships with families and friends resulted in significant support for their diabetes management. Furthermore, some participants' stories, most notably the females, illustrated the visibility of living with diabetes and their efforts to minimize that visibility.

### Support from Families and Friends

Adolescents' lives are relational and the lives of participants in this study were no exception. While relationships with friends dominated adolescents' lives, relationships with families were also very much in the foreground. Given the nature of diabetes management and the recognition that an interdependent relationship is useful, supportive, and desirable (La Greca et al., 1995; Schilling, Grey, & Knafl, 2002; Kyngas & Barlow, 1995; Kyngas & Hentinen, 1995; Kyngas, Kroll, & Duffy, 2000), it was interesting to note that the findings from the current study supported this view. Furthermore, Paterson and Thorne (2000b) and Thorne and Paterson (2001) reported a similar need in adults for dependence on others particularly in times of stress or crisis indicating that, regardless of age, interdependent relationships may be appropriate or desirable for individuals with diabetes.

In the present study, mothers, in particular, offered considerable practical support and participants appreciated it, expected it, and they sometimes asked for it. In addition to the importance attributed to the maintenance of an interdependent relationship between adolescents and their families, several studies revealed the importance of support from families (Christian, D'Auria, & Fox, 1999; Hanna & Guthrie, 2001; Kyngas, Hentinen, & Barlow, 1998; La Greca, 1992; La Greca et al. 1995; Lo, 1999; Rubin, 2001; Woodgate, 1998a).

While support from families is crucial, findings from the present study indicated that parental involvement was not always positive. Parents' questioning of their adolescents' diabetes management was sometimes perceived as over-involvement and resulted in behaviors such as an unwillingness to share diabetes-related information or,

on occasion, fabrication of blood sugar values; behaviors that would be deemed undesirable by parents, and, indeed, were considered guilt-inducing by the adolescents themselves. Furthermore, the intrusive nature of parental questioning heightened the visibility of diabetes in adolescents' lives.

Findings from Kyngas and Barlow's (1995) study indicated that lying to family members and health care professionals represented adolescents' way of coping with unrealistic expectations and was a means of ensuring that relations with families and health care professionals were bearable. Weissberg-Benchell et al. (1995) supported the notion that adolescents fabricated blood sugar results because they felt pressured by families and physicians to report "good" blood sugar levels. Hernandez, Bradish, Spence Laschinger, Wilson Rodger, and Rybansky (1997) maintain that there is a fine line between intrusive and supportive behaviors.

While tangible support is most commonly associated with parental support (La Greca et al., 1995), most adolescents in La Greca et al.'s research also reported emotional support from families. Findings from Christian, D'Auria, and Fox's (1999) study indicated that adolescents wanted independence but recognized the necessity of help with meal planning and praise for their achievements. Finally, of considerable interest and surprise to me was La Greca et al.'s finding that nagging was perceived by a small proportion of the adolescents to be supportive. Interestingly, in the current study, Roger described the parental support he received as nagging.

Support from friends is seldom alluded to in the research studies with adults and its emphasis in the adolescent literature may reflect the importance of friends and peers to this population. Several studies indicated the importance of supportive friendships

(Christian, D'Auria & Fox, 1999; Kyngas, Hentinen, & Barlow, 1998; La Greca, 1992; La Greca et al. 1995; Rubin, 2001; Woodgate, 1998a).

There is little doubt that adolescents are often seen in a negative light (Clark, 1998; Weissberg-Benchell & Antisdel, 2000) and peers are often assumed to be a negative influence. While Woodman (1999) speculates that such negativity might occur when a need for acceptance amongst peers is stronger than the need to attend to diabetes management, and findings from Kyngas, Hentinen and Barlow's (1998) study supported this view, there were numerous reports that upheld the findings from the current study that indicated the value of friends' support for diabetes management (Christian, D'Auria, & Fox, 1999; Kyngas & Hentinen, 1995; Kyngas, Hentinen, & Barlow, 1998; La Greca 1992; La Greca et al. 1995; Rubin, 2001; Skinner, Petzing & Johnston, 1999; Woodgate, 1998a). Furthermore, the type of support received from friends was both tangible and emotional, with the latter described as more valuable than the former (Skinner, Petzing & Johnston, 1999). Also, La Greca (1995) described the companionship support that adolescents received from friends. Supportive behaviors included friends not buying high sugar treats (Kyngas & Hentinen, 1995), changing lifestyle to adapt to the needs of the adolescent with diabetes (Kyngas & Hentinen, 1995; Kyngas, Hentinen, & Barlow, 1998; La Greca et al., 1995), and helping adolescents to feel good about their diabetes (La Greca et al., 1995).

### Visibility/Invisibility

Findings from this study support the notion that diabetes is visible and participants made decisions and concentrated efforts to reduce or eliminate the visibility of both a diabetes identity (Thorne, 1999) and diabetes management on a regular basis.

Joachim and Acorn (2000a; 2000b) conceptualize diabetes as an invisible condition. Findings from the present study refute this perspective. Furthermore, Schreiner, Brow, and Phillips (2000) describe the use of ID tags such as MedicAlert bracelets as illustrative of diabetes' visibility. However, these are not mandatory, and can be worn as a pendant under clothing, thus rendering them potentially invisible.

Participants in the current study described the implications of living with and managing diabetes in the social arena. In particular, the females described efforts to maintain invisibility in social situations so that strangers would not be privy to tasks such as insulin administration. Their fear of being perceived as a drug addict should they inject insulin in public was supported by others (Meldman, 1987; Skinner, Petzing & Johnston, 1999). Sadly, Skinner, Petzing and Johnston's research revealed that other adolescents had actually labeled adolescents with diabetes as a "druggie" or similar terms. Further evidence for the notion of the visibility of diabetes is illustrated in the findings from several studies indicating participants' fears of hypoglycemia in public (Callaghan & Williams, 1994; Dunning, 1995), and efforts to prevent the visibility of hypoglycemia included strategies to maintain high blood sugar levels (Timms & Lowes, 1999).

In the United Kingdom, findings from Williams's (2000) research differentiated between female and male responses to visibility in the public arena. Williams reported that the females administered insulin in public places and the male participants chose private settings. She interpreted this to indicate that the female participants incorporated diabetes into their identity whereas the male participants did not. She speculated that such responses should be viewed in the context of gendered identities. Findings from the

present study contradict Williams's findings, as the females in this study were more concerned with invisibility than were their male counterparts.

Findings from the current study revealed that diet is the most bothersome aspect of living with diabetes, a finding that is strongly supported in both the adult and adolescent literature (Ahern & Grey, 1996; Callaghan & Williams, 1994; Coates & Boore, 1995; Faro, 1999; Standiford et al., 1997; Weissberg-Benchell et al., 1995). Furthermore, diet restrictions have social implications (Christian, D'Auria, & Fox, 1999; Faro, 1999; Paterson & Thorne, 2000a) that often make the invisibility of diabetes visible (Thorne & Paterson, 2001), and it is this visibility that may threaten social relationships (Thorne & Paterson, 2000).

Finally, findings from the present study indicated a link between visibility and illness disclosure. In one instance illness disclosure resulted in the young adolescent feeling stigmatized. Joachim and Acorn (2000a) suggest that the invisibility of diabetes allows individuals to conceal their illness status. These authors maintain that disclosure reluctance may be associated with assumptions that others' responses may be negative and individuals may be selective to whom they disclose in order to avoid stigma. Indeed, participants in the current study were quite selective with whom they shared their illness status, and when they deemed it appropriate, usually to maintain safety, they disclosed their illness status cautiously. Several authors (Hernandez, 1996; Meldman, 1987) have identified the social importance of illness disclosure.

All in all, diabetes is a potentially visible chronic condition. Despite some authors' assertion that this is not so, several authors, in addition to the findings from the

current study, attest to its visibility. In addition, the social implications of such visibility may be significant and those implications may differ within gender and cultural contexts.

### Socio-Political Context

Everyday decision making was enacted in the context of the health care system. In particular, I came to understand the nature of relationships with health care professionals, the relevance of illness-specific support groups, and the value of health care economics, to overall decision making and diabetes management of the adolescents in this study.

### Relationships with Health Care Professionals.

Although the role of health care providers in adolescents' diabetes management is often ambiguous (Schilling, Grey, & Knafl, 2002), and findings from Hentinen and Kyngas' (1996) study uncovered no relationship between the support given by physicians or nurses and the assessment of compliance by adolescents with diabetes, several authors attest to the importance of positive relationships between individuals with diabetes and their health care providers (Kyngas, Hentinen, & Barlow, 1998; Kyngas, Kroll, & Duffy, 2000; Lo, 1999). Although adults appear to appreciate the support offered by formalized groups, participants in the current study revealed their lack of interest and distaste for illness-specific support groups mostly because they believed that placing diabetes as the focus of a relationship was unappealing. Moreover, as the focus of most support groups is the chronic illness (Paterson, 2001a), this could potentially increase visibility of diabetes and possibly reinforce a 'diabetic identity'

Findings from this study portrayed relationships with health care professionals as "background" relationships because interactions were regular but rare. Participants in this study identified the infrequency of interactions as a deterrent to the establishment of a

relationship. The increasing incidence and prevalence of pediatric diabetes in British Columbia have resulted in fewer health care professional resources for individuals. Essentially, the six-month check up at the ambulatory clinic at the local pediatric hospital has now become the eight month or greater visit (Metzger, personal communication, 2001). However, relationships with health care professionals do remain relatively stable, at least until adolescents make the transition to adult health care services.

Participants in the current study felt respected by their health care providers. One might assume that health care professionals valued adolescents' expertise as they had nominated them for this study. Indeed, there was an incident when a physician's trust in Samantha's body signals reflected a rather sophisticated level of confidence in her experiential knowledge. Interestingly, findings from Paterson's (2001b) research revealed that fifty percent of participants viewed collaborative decision making with health care providers as rare even though they had been nominated as successful in their diabetes management. Findings from Thorne, Ternulf Nyhlin, and Paterson's (2000) secondary analysis of two studies indicated that all adult participants depicted relationships with health care professionals that were distinguished by a lack of trust in participants' decision making competence.

Similarly, in the current study, there were occasions when adolescents felt judged and blamed by health care providers, particularly in the realm of high blood sugar values. Although the team never admonished the adolescents verbally, participants perceived a sense of disapproval that caused them to feel blamed and guilty. Bennett Johnson (1995) agrees that adolescents are often inappropriately blamed for high blood sugar values rather than receiving recognition for a variety of causes for hyperglycemia such as insulin

resistance. Additionally, a focus on blood sugar values accentuates the importance of outcomes rather than process; such an emphasis, in the context of clients' decision making, is recognized by many researchers as narrow and problematic (Bottorff et al., 1998; Ramirez Basco, 1998).

Further, in order to foster a tolerable relationship with health care providers, adolescents may lie when they perceive health care providers' expectations as unreasonably high (Kyngas & Barlow, 1995; Weissberg-Benchell et al., 1995) and such behavior results in a lack of trust (Kyngas & Barlow, 1995). Some adolescents in the current study reported that health care professionals' expectations were sometimes unreasonable and unrealistic. The importance of initiating positive relationships with adolescent clients cannot be overemphasized as positive experiences with providers in adolescence may foster similar health care relationships in the future (Weissberg-Benchell & Antisdel, 2000).

All in all, relationships with health care providers should be collaborative in nature (Clark, 1998; Schilling, Grey, & Knafl, 2002; Paterson, 2001b), respectful of individuals' knowledge and expertise (Callaghan & Williams, 1994; Coates & Boore, 1995), attentive to the personal and social context of individuals' lives (Paterson & Thorne, 2000b), and mindful of the power issues inherent in such relationships (Callaghan & Williams, 1994; Dickinson, 1999). Although the adolescents in the present study had infrequent interactions with their health care providers and did not place great emphasis on those interactions, it is worth noting that their perceptions of feeling respected and treated as individuals were combined with feeling judged and blamed by the health care team. Thorne and Paterson (2001) maintain that the support that

individuals need is variable and dependent on the level of individuals' expertise. It is feasible that the adolescents in this study had reached the point where their need for health care professional involvement was minimal. Alternatively, adolescents are in the unique position, compared to adults, of having parents as "mediators" and this interdependence and collaboration with parents may influence their reliance on health care professionals. Regardless of the perceived value of current relationships that adolescents have with their health care team, it is worth remembering that the nature of the relationship in adolescence may well "set the stage" for relationships with health care providers in the future (Weissberg-Benchell & Antisdel, 2000).

### Economics

Diabetes is a costly chronic illness at the individual, social, economic, and health status level. Diabetes management and lack of diabetes management is costly (Lo, 1999; Nordfeldt & Jonsson, 2001). The health care restructuring that is occurring in Canada is affecting many of the services for individuals with chronic illness (Thorne, 2000). One such service is the accessibility of health care provisions and diabetes management supplies such as blood sugar testing equipment. Findings from this study revealed that adolescents with expertise perform blood glucose monitoring on a regular basis, usually three times daily and more frequently in certain situations. It is my interpretation that neither the participants nor their families experienced financial hardship as a result of such regular blood glucose monitoring. Nevertheless, it is worth noting that the test strips required for blood glucose monitoring are the most significant cost of diabetes management as each strip costs close to one dollar apiece. There is little doubt that

individuals may omit or reduce such monitoring if costs are problematic (Paterson, Russell & Thorne, 2001).

In British Columbia, Canada, Pharmacare's Universal Plan E provides coverage for those residents who are not covered under specialized plans such as those designed for persons receiving medical benefits from the Ministry of Human Resources. (Pharmacare [online], 2002) Under Plan E, families or individuals pay an annual deductible of \$1000. A deductible is an annual amount that must be paid entirely by the individual on insured products before the insurer begins to pay a portion of the costs. Pharmacare pays seventy per cent of the cost of blood glucose monitoring strips exceeding the deductible. Once the individual or family pays \$2000 in total per year in costs Pharmacare will then cover all further costs for that year. In January 2002, the deductible was increased; from \$800 to \$1000. For individuals or families who receive MSP Premium Assistance, the deductible remains significant at \$800 although further eligible annual costs are fully covered. (Pharmacare [online], 2002). Specific items such as blood glucose monitors, lancets, and insulin pumps are not covered. Such policies are very short sighted and fail to recognize the enormous long-term costs of inaccessibility to crucial management tools. Further, such policies are in conflict with the ideals of the Canada Health Act

There has been minimal research into the chronic illness experience of individuals who are poor (Thorne & Paterson, 2000). Unfortunately, this current research is no exception and it is unclear whether adolescents with limited financial sources who do not have access to equipment would be perceived as having expertise, and be nominated for this study. Health care practitioners often make recommendations to clients without

acknowledging the financial constraints with which individuals live (Paterson, 2001b).

Acknowledgement should be given to the socio-political and socioeconomic constraints placed on individuals and the difficult life circumstances of individuals with chronic illness (Hunt, Arar, & Larne, 1998). Further work is needed to explore the notion of expertise within such constraints.

For example, if adolescents with diabetes maintain a positive attitude, develop scientific and experiential knowledge, are influenced by the future, have supportive family and friends, but are unable to afford a glucometer and/or the test strips required for its daily use – does this place them in a vulnerable position in terms of having expertise, in terms of quality of life, and in terms of future complications? I believe that it does and that, as nurses, we have a responsibility to make visible and attempt to change the socioeconomic inequities with which these clients struggle (Thorne, McCormick, & Carty, 1999).

In summary, adolescents' everyday decision making was influenced by a number of contexts. Individual contexts included participants' personal characteristics such as attitudes and knowledge. Although the implications of gender were subtle they were not neutral. The social context of participants' lives comprised a significant portion of the overall findings, as adolescents' lives were strongly relational. This is not surprising given the nature of adolescents' lives in general. Finally, the socio-political environment, as illustrated by relations with health care providers and the economics of health care delivery and access, was crucial to a broad understanding of expertise in diabetes management.

### **“Doing” Research with Adolescents**

“Doing” research with adolescents who were nominated as having expertise in their diabetes management resulted in some interesting findings related to participant recruitment, participant fit, methods of data collection, and ambiguity around the definition of expertise. These findings are, in my view, as relevant as the substantive findings described earlier in this chapter.

#### The Process

The research process included a recruitment strategy that relied on a nomination procedure. This technique resulted in some ambiguity around “participant fit” and might have been avoided, or at least minimized, had I been clear in my nomination criteria guidelines. The research process also included a variety of data collection methods; this variety contributed to the richness of the data. In this section, I discuss both the recruitment strategy and data collection methods used in the study.

#### Nomination-Style Recruitment Strategy

The nomination-style recruitment strategy that I used was somewhat problematic in terms of “participant fit.” Specifically, participants were nominated by a health care professional although not all health care professionals were involved in a professional relationship with those they nominated. Regardless of the specific nature of the relationship between participants and nominators, problems with this process had potential implications for the study’s integrity. Reflecting on and attending to the consequences of the problems associated with the nomination process allowed me to enhance rather than detract from the study’s integrity. For example, had I ignored the ambiguity I felt around Roger’s inclusion and interpreted his data in a similar manner to

other participants I would have hindered the credibility of the findings and the overall impact of the study. Keeping this in mind, it is important to acknowledge that, as researchers, we have an obligation to assume that readers of our work may change their practice based on our findings, thus making a study's integrity even more crucial. I believe that the looseness of my definition of expertise contributed to the difficulties associated with the nomination-style process of recruitment.

#### The Interplay between Collection Method(s) and Data

Adolescents' ways of sharing knowledge depended somewhat on the context. The use of a variety of data collection strategies enabled me to access adolescents' stories in a comprehensive manner and facilitated a depth, a richness, and an honesty that would have been, I believe, virtually impossible had I conducted individual interviews only. There is little doubt that a single method of data collection would have resulted in different findings and ultimately a different study.

It is likely that the reasons for this are complex. First, my style of interviewing participants individually versus as a group may have played a part in the way adolescents responded. There were occasions, for example, when I noted differences in my questioning style in one context versus the other. Second, my relationships with participants developed over time and in a variety of settings and this may have resulted in a trust that facilitated disclosure during later, rather than earlier, interviews. Clark (1998) recommends that health care professionals avoid judgmental or paternalistic behaviors and suggests that practitioners reassure adolescents that they are not parent surrogates. I believe that my personal disclosure at the focus group might have resulted in some anxiety among participants had they perceived our relationship to be paternalistic or had

they viewed me as a parent surrogate. Indeed, some participants expressed the view that, had they known my personal location from the outset, they would have perceived me as a potentially judgmental parent substitute rather than a researcher and would have been less inclined to share certain information with me.

I tried, at the individual and group level, to foster an environment in which adolescents felt safe. Also, I made a conscious effort to be non-judgmental in my approach with participants. It is my belief that participants did feel respected and safe thus supporting the view that the context of the researcher/researched relationship contributed to the final information that adolescents shared.

Third, I suspect that it was the type of data collection method that supported many adolescents' disclosures. Specifically, group process appeared to foster disclosure-type discussions and my findings in this regard supported Morse and Field's (1995) claim that data generated in individual and group interviews are significantly different. Further, Robinson (1999) explains that focus groups allow researchers to use communication styles or strategies that may be inappropriate in the individual interview thus facilitating new data generation. The findings from this study supported this view. It is feasible that focus groups may be particularly useful for this population. Interestingly, even though some participants appeared to connect quite well, they remained adamant that illness-related support groups would be unappealing.

Finally, it is unclear whether a focus group at the beginning of the research process would have resulted in the same data generated from a focus group at the end of the research process. It is possible that the safe environment and the trust that developed over time and throughout a series of interviews contributed to the data's richness. It is unknown if this would be feasible should the order of the data collection strategies be

reversed. Therefore, regardless of the order, it seems prudent to consider a variety of collection methods in order to access the richest data possible.

### The Ambiguities

In Chapter Two I agreed with the authors who argued convincingly against the suitability of the use of the concept of compliance in the context of chronic illness. Consequently, I did not attend to the notion of compliance throughout the research process. However, there is an abundance of attention given to the notion of compliance in the literature and while some researchers conceptualize compliance in the traditional sense of complying with health care professionals' recommendations, others, particularly in nursing, understand compliance to encompass a much broader perspective (Hentinen & Kyngas, 1996). Thorne (1990) maintains that simply substituting terms such as adherence for compliance does not change the issues of power that are embedded in the notion of compliance.

Although compliance was not a focus in the current study, my re-examination of the literature encouraged me to ponder the potential links between the willingness of participants in this study to consistently perform the numerous everyday tasks that are frequently touted as evidence of compliance or adherence to self-care (Dickinson, 1999; Grey & Sullivan-Bolyai, 1999; Hentinen and Kyngas, 1996; Kyngas & Barlow, 1995; Kyngas, Hentinen, & Barlow, 1998) and question the possibility of a link between expertise and compliance as it is currently conceptualized. Might aspects of compliance, blood glucose monitoring for example, be an important aspect of expertise?

Furthermore, how might the notion of compliance relate to the reasons underlying adolescents' nominations by their health care providers? In a sense, I could make a link between participants' use of scientific principles and recommendations by health care

professionals, thus connecting an aspect of expertise (as understood in this study) to compliance. Although attention to scientific knowledge was limited in its utility, it was valuable. While it may be prudent to consider the notion of compliance as being semantically and philosophically problematic as a total management strategy (in the context of chronic illness management), it may be worth conceptualizing it as a useful and important component of expertise in its entirety. Health care professionals' expertise would then be valued as an important component of the scientific knowledge that was inherent in the findings of this study.

Thorne and Paterson (1998) maintain that the current trend in the literature towards acknowledging individuals' expertise and embracing a collaborative partnership-style relationship runs the risk of ignoring the ongoing need that many individuals with chronic illnesses have to solicit and count on help from professional experts. Within the concept of collaborative relationships is the notion of clients as co-experts (Hernandez, Bradish, Spence Laschinger, Wilson Rodger, & Rybansky, 1997). Findings from Thorne, Ternulf Nyhlin, and Paterson's (2000) research indicated that health care professionals were unwilling to relinquish the role of expert despite their actual non-expertise in the area of diabetes management. In addition to the notion of client as co-expert, perhaps the shift from professional expert to that of co-expert also needs to occur.

Findings from Ellison and Rayman's (1998) study of women with type 2 diabetes who were nominated as "exemplars" revealed that the women were sometimes amazed to have been nominated for the study. Findings from the current study supported this observation, as adolescents were usually surprised to have been nominated as experts in their own care. It is interesting to note that participants in the current study were unaware

of their own expertise and this observation leads me to assume that they were unused to receiving praise from health care professionals for their ongoing accomplishments and a job well done. On a personal level, I have experienced responses from both health care professionals and the general public assuming that, although I am the parent of a child with diabetes, it is my nursing “expertise” that is of immeasurable value in the day-to-day management of my daughter’s diabetes, thus illustrating, in my view, how expertise in chronic illness is viewed and valued at a societal level.

There was significant ambiguity around my definition of expertise and it was this ambiguity, in part, that resulted in issues with “participant fit.” For the purposes of this study, expertise was understood when health care professionals recognized an adolescent as being more skilled than most at diabetes self-care decision making. In similar adult-focused research, Paterson and Thorne (2000a) guided nominators by defining expert self-management as “the ability to make trustworthy decisions about self-management and to maintain good overall glycemic control” (Paterson, 2001b, p. 576). Even though I was guided by these authors’ nomination-style process, I made a conscious decision to omit glycemic control as a criterion for nomination. I made this decision because of the inherent risk of nominators focusing on outcomes rather than process. However, it is quite likely that nominators were cognizant of glycemic control, as evidenced by Halc values for example, as they considered potential nominees. In hindsight, I recognize that it would have been useful to have clearly articulated my concerns. Moreover, there may have been some value to accessing participants’ glycemic values and interpreting them in the context of adolescents’ expertise. I did attempt to discover participants’ Halc’s but I

did so informally and there was, on occasion, a degree of uncertainty about results. Consequently, I chose not to incorporate these reports into the study.

I had hoped that, by loosely defining expertise, the nomination process might lend itself to adding to the scant body of knowledge about expertise in adolescents. However, the nominators with whom I spoke explained that they relied on my definition and were rather loose in trying to identify their rationale for nominating the adolescents as having expertise. This is not surprising given my lack of structured direction.

Could I define expertise more clearly based on the findings in this study? I do not think that this small study's findings allow me to define expertise in adolescents with type 1 diabetes. Several researchers have investigated, and continue to explore, the concept of expertise as it relates to adults with diabetes. Most notable is the work of Paterson and Sloan (1994) and Paterson and Thorne (2000a; 2000b) whose research identified many of the variables reported in the current study with adolescents. In particular, the development of expertise included active management, body knowing, development of collaborative relationships, fostering support (Paterson & Sloan, 1994), an ongoing process involving body awareness, maintenance of a regular routine, blood sugar monitoring, knowledge, contextual factors, and a sensible attitude (Paterson & Thorne, 2000a; 2000b). Further, Hernandez (1996) identified experiential learning, experimentation, and body awareness as important components of expertise. Although many of these components of expertise were identified in the current study, it is feasible that adolescents' expertise may need to be defined differently from that of adults, as adolescents are not mirror images of adults (Woodgate, 1998). However, the findings from this study revealed that "expertise" in adolescence is thriving although neither well

defined nor clearly articulated at this time. This is a powerful finding, as adolescence is commonly perceived as a time of non-expertise. For example, when I was having difficulty with recruitment (i.e. finding suitable participants with expertise) colleagues implied that it was not surprising given the population that I was researching. Their implication was clear; adolescents do not have expertise.

Despite the challenges associated with defining expertise, the study did allow me to compare a participant without expertise (both in his view and mine) to others in the study. It is often useful to identify what a concept is not in order to identify and articulate what it actually is. Furthermore, Roger's conceptualization of expertise as comprising knowing and doing enabled me to begin to deconstruct the concept of expertise and to consider expertise as having two components; relatively discrete components in Roger's case but less discrete from the perspective of other participants.

It is also reasonable, in my view, to make a connection between the elements of expertise and the art and science of everyday decision making that were discussed in Chapter Four. For example, while not exclusive, expertise in knowing might equate with scientific knowledge whereas expertise in doing might be played out as the art of everyday decision making. Of further interest is the hypothesis that there may be a link between expertise and the contexts discussed in this chapter. For example, expertise may be dependent on individuals' attitude and knowledge, supportive families and friends, ongoing, positive relationships with health care professionals, and a health care system that facilitates the practical aspects of diabetes regardless of socioeconomic status. These hypotheses are tentative and preliminary and are simply a first step in attempting to

understand an extremely complex concept: that of expertise in adolescents with type 1 diabetes.

Overall, “doing” research with adolescents nominated as having expertise in their diabetes management was a process that resulted in ambiguities, questions, and tentative hypotheses. From a novice researcher’s perspective, I was as fascinated with the research process as I was with the substantive findings inherent in the study. The recruitment strategy, the variety of data collection methods, and the ambiguity around the definition of expertise contributed to my fascination, and ultimately to my understanding of the process “findings.”

### **Summary and Conclusion**

The findings from this study represent some of the experiences of adolescents with diabetes as they used their expertise to make everyday decisions. In this chapter, I have emphasized selected key findings that struck me as particularly interesting and relevant for discussion. These findings include the contexts in which adolescents with diabetes live their lives and make decisions, moment-by-moment, and day-by-day.

The everyday decision making of the adolescents in this study was strongly influenced by their scientific and experiential knowledge, their ability to apply such knowledge, their use of scientific tools, their pragmatic and positive attitude, their willingness to maintain regular routines, and their attention to minimizing future complications.

The gendered context of adolescents’ decision making was subtle. The females in the study understood friends as being caringly supportive and devised ways of staying invisible within the context of having and living with diabetes. While the males were less

concerned with the visibility of diabetes, it is less clear as to whether they perceived their friends as being consciously supportive of their diabetes and its management.

Adolescents' lives and their diabetes management were embedded in relationships with families and friends. Supportive friendships were of notable value to the adolescents in this study and friends were quite influential in their everyday decision making. Families, particularly mothers, provided participants with significant support and the importance of the interdependent relationships described in this study were strongly supported in the adolescent literature. However, support was not always positive and families' focus on adolescents' diabetes sometimes resulted in less-than-ideal behaviors such as fabrication of blood sugar values.

In addition to relationships with friends and families, connections with health care professionals and others with diabetes were explored. Participants placed little emphasis on their relations with health care providers and they clearly articulated their disinterest in illness-related support groups. These are interesting findings given the assumption of the importance that many health care providers might ascribe to these relationships. Further, the adolescents in this study appeared to be somewhat "privileged" in terms of health care access. This observation encouraged my examination of health care access for individuals with fewer financial resources and motivated me to ponder the potential link between socioeconomic status and expertise.

There were also some findings relating to the research process that I deemed worthy of inclusion in this chapter's discussion. In particular, the nomination-style recruitment strategy allowed me to try to access health care professionals' understanding of expertise in this population. Regrettably, this strategy was less successful than I had

anticipated and I am no wiser in this regard. However, the way in which I guided and conducted the recruitment process could pave the way for future research using similar recruitment strategies. Specifically, I would clearly articulate, from the outset, some guidelines for the nomination process.

In addition, the findings from this study facilitated an exploration of the notion of expertise in adolescents' diabetes management. There may be some links between expertise in diabetes management and adolescents' scientific and experiential knowledge, their ability to apply such knowledge, their use of scientific tools, their pragmatic and positive attitude, their willingness to maintain regular routines, and their attention to minimizing future complications (these specific characteristics were linked to everyday decision making earlier in this section). In addition, expertise in diabetes management may be fostered by supportive relationships with families and friends and may rely on a degree of support from health care professionals although the latter may be minimal as adolescents develop expertise. Finally, expertise may be dependent on access to health care; specifically access to the tools such as blood glucose monitoring devices that were a significant part of participants' everyday decision making strategies.

In a sense, the findings from this study have resulted in more questions than answers. They have stirred my curiosity, promoted some thoughtful reflections, and will encourage an ongoing journey towards answering some of those unanswered questions.

## CHAPTER SIX: SUMMARY, CONCLUSIONS, AND IMPLICATIONS

### **Summary of the Study**

The purpose of this study was to explore how adolescents with type 1 diabetes who were nominated as having expertise make everyday decisions. In general, participants were surprised to be nominated as having expertise and, although they clearly articulated the complexities inherent in the day-to-day management of diabetes, they tended to minimize the extraordinary demands placed on them so that they could pragmatically get on with life.

Six adolescents were nominated and invited to participate in this study. With one exception, participants shared many of the characteristics and behaviors that comprised the themes inherent in the study's findings. All participants were interviewed twice. In addition, four participants conducted a think-aloud procedure while the remaining two adolescents substituted a series of mini telephone interviews. Finally, five adolescents participated in a focus group during which time I shared my emerging interpretations of the data. The variety of data collection methods contributed to the wealth of the study's conclusions. All data were transcribed verbatim and data collection and analysis occurred concurrently although there was a significant portion of analysis that occurred following completion of the data collection process.

Adolescents' everyday decision making comprised an art and a science and both were enacted in the social context of adolescents' lives. Broadly, the science underlying everyday decision making was general and somewhat acontextual therefore of limited but crucial value. The art of decision making compensated for some of the limitations of adolescents' use of science. In particular, the art of everyday decision making recognized

the uniqueness and context of participants' lives. The art sometimes complemented the science of decision making, sometimes relied on it, and sometimes replaced it. Both the art and science of decision making were grounded in participants' social context.

Over time, I came to understand that there were important contexts within the broad themes of art, science, and social context. These contexts represent the findings from this study that I deemed significant as I tried to understand the expertise that was inherent in participants' accounts of their everyday decision making. Their personal characteristics, social relationships, and experiences with the health care system all played a role in the everyday management of their chronic illness. The implications for nursing are based on these findings.

Further, the research process resulted in findings about recruitment strategies, methods of data collection, and issues with concept definition and clarity. Many of the implications for future research are based on these process findings.

### **Conclusions**

The conclusions outlined in this section illustrate an emphasis that I have placed on selected key findings; ones that I deemed of notable relevance to nursing.

1. Expertise in adolescents with type 1 diabetes is neither well understood nor well articulated at this time. Nevertheless, the nominations and findings from this study suggest that expertise is alive and well. In addition, conceptualizations of expertise in the adult literature reflected many of the findings in this study, leading me to conclude that, while adolescents are not adults, there may be significant resemblances in the expertise of adolescents and their adult counterparts.

2. Participants' everyday decision making was an art and a science. The science of everyday decision making was somewhat acontextual whereas the art emphasized the uniqueness and individuality of adolescents' lives. Each complemented the other and both were significant components of diabetes management.
3. The art and science of everyday decision making were enacted in the social context of participants' lives. The social context comprised adolescent culture and relationships with families and friends. Participants' behaviors and decision making were influenced by the type of support given by families. Furthermore, supportive friendships were influential in adolescents' everyday decision making. Female participants were particularly cognizant and appreciative of friends' caring support.
4. Diabetes is a potentially visible chronic illness and female participants devised ways of maintaining invisibility. Female participants were more concerned about the visibility of diabetes than were their male counterparts. Although diabetes is not physically visible to others, many of the everyday management strategies make it so, especially in the social realm.
5. Relationships with health care providers were not at the forefront of participants' lives. However, participants described elements of existing relationships with the health care team as respectful and supportive as well as judgmental and demanding.
6. Participants shared their lack of interest in support from illness-focused support groups. Some adolescents believed that diabetes should not be the focus of

potential friendships while others recognized that they received all the support they needed from families and friends.

7. Everyday decision making was embedded in participants' pragmatic and positive attitude, scientific and experiential knowledge, application of such knowledge, and attention to the future. Of particular note were the body signals that participants knew, listened to, checked, or ignored. These signals developed over time and with experience and were used in conjunction with blood glucose monitoring.
8. Participants' everyday decision making relied on access to health care services and supplies such as blood glucose monitoring devices. Participants never mentioned issues with such access thus leading me to assume that access was unproblematic.
9. The use of a variety of data collection strategies resulted in a wealth of data that might not have been feasible had I relied on a single method. It is likely that the group dynamics inherent in the focus group facilitated certain data that might otherwise have remained hidden.
10. Finally, attending to participant "fit" and including an outlier in my ongoing data collection and analyses furthered my thinking and understanding of many of the findings in this study and, in a sense, enhanced the study's credibility. Further, exploring an outlier's perspective alerted me to the realization that there are likely many other adolescents living with diabetes that would neither nominate themselves nor be nominated by others as having expertise in their diabetes management.

## **Implications for Practice, Education, and Research**

It is here that I need to ask myself the “so what” question. Doing so leads me to consider the implications of the findings from this small qualitative study for nursing practice, education and research. While there are implications for education and research, it is in the practice realm that the implications are most evident.

### Implications for Practice

The findings from this study revealed that expertise was inherent in participants' everyday decision making. Health care providers, parents, and adolescents themselves recognized this expertise although it was neither clearly articulated nor well defined. Nevertheless, practitioners nominated participants as having expertise, mothers spoke enthusiastically and positively about their adolescents' diabetes management, and the participants agreed, when questioned, that they did indeed have expertise in their self-care.

Interestingly, adolescents in this study were unfailingly modest about their expertise and none shared stories of having been congratulated on how well they were doing or on having had such expertise acknowledged. In my view, it is crucial from a practice perspective to be able to clearly define clients' expertise so that nurses can detect it, acknowledge it, and incorporate it into nursing practice (Williams, 1999). Doing so may foster the development of expertise in adolescents who do not have it and enhance expertise in those who do. Yet, without a clear understanding of what exactly expertise is, operationalizing it at the practice level remains problematic. Consequently, there is little doubt that further work at the theoretical and empirical level is needed to understand this concept as it relates to adolescents with type 1diabetes. In the meantime, nurses need to

remain open to the notion of expertise in their young clients and try to understand adolescents' expertise at a clinical level.

Despite the fact that adolescents were nominated as having expertise and their belief that relationships with health care providers were respectful, many participants in the current study felt that, while never stated verbally, practitioners sometimes had unrealistic expectations of their clients and judged them harshly if blood sugar levels were on the high side. It is important for nurses to avoid placing unrealistic expectations on adolescents' shoulders (Kyngas & Barlow, 1995) and to recognize the limitations of using blood glucose values as the sole measure of individuals' management expertise (Paterson & Thorne, 2000b). Instead, it would be prudent for nurses to discuss the many reasons for hyperglycemia, to role model non-judgmental attitudes towards adolescents' high blood sugars, and to talk openly with adolescents about issues such as fabricating blood sugar results. Such role modeling might be particularly beneficial for parents given the finding in this study that parental attitudes sometimes resulted in adolescents' withholding or fabricating blood sugar values.

Although compliance was not a focus in this study, it is worth noting that "took extra insulin to cover food" was considered mismanagement and was reported by 47% of females and 31% of males in Hanna and Guthrie's (1999) study with adolescents. In the current study, adolescents reported taking insulin to cover extra food at mealtimes but seldom did so for high sugar or snack foods and explained that they were seldom encouraged to do so by the health care team. It may be that practitioners need to consider ways to redefine mismanagement. For example, regularly eating a chocolate bar may be manageable as long as short acting insulin such as Lispro is given to counteract the

potential hyperglycemia that might otherwise occur. Perhaps practitioners could promote this type of management proactively instead of discouraging it from the outset or indeed judging it as mismanagement. In so doing, it might foster an individual-focused or “negotiated” compliance that might allow individuals to fit diabetes into their lifestyle rather than trying to fit their lifestyle into diabetes.

The findings from this study revealed the importance of interdependent diabetes management and supportive relationships with families. Nurses need to be aware of these relationships so they can foster interdependence between adolescents and families rather than trying to encourage adolescents to become independent (Williams, 1999). Furthermore, adolescents and their families need to be aware of the positive benefits of such relationships yet, at the same time, they need to be cognizant of the fine balance between support and intrusion (Hernandez, Bradish, Spence Laschinger, Wilson Rodger, & Rybansky, 1997). Parents may need guidance in achieving this balance (Kyngas, Hentinen, & Barlow, 1998).

In an effort to facilitate parental needs, nurses could design ways to communicate with parents as many adolescents are encouraged to visit the diabetes team alone and parents are seldom involved directly with their adolescents’ health care visits. While this is obviously an important strategy for adolescents’ development and independence it may be detrimental in terms of promoting a degree of parental isolation. Mothers in particular may appreciate such support given the findings from this study that suggested it was mothers who were the primary supportive family member. In order to maintain adolescents’ confidentiality yet at the same time meet parents’ needs it may be useful to consider educational and support sessions for groups of parents. In this way,

confidentiality of the individual would be maintained, needs of parents could be met, and a relationship between nurses and the family could be fostered.

In addition to the importance of familial support, the findings of this study revealed the importance of supportive friendships. Nurses need to consider the importance of friendships to adolescent clients and to consider ways of fostering peer support. For example, in this study, friends were supportive by maintaining active lifestyles, discouraging consumption of high sugar foods, and making restaurant choices that were congruent with the diabetes meal plan, thus illustrating the importance of including friends in the health team's overall management plan.

In this study, it was interesting to note that even though Roger appeared to have many friends, they neither maintained active lifestyles nor discouraged his consumption of high sugar foods. Nurses need to assess the type of support that adolescents are receiving from their friends. Given the importance of supportive friendships, La Greca et al. (1995) remind practitioners to be on the alert for adolescents with few friendships, or adolescents who may be uncomfortable disclosing their illness status as they may lack a crucial source of support for their diabetes care.

Finally, based on the analysis of this study, nurses should not assume that individuals have the necessary resources to agree to common diabetes management recommendations such as frequent blood glucose monitoring. As nurses, we have a responsibility to sensitively assess our clients' potential lack of resources and ensure their access to these resources when such a lack is identified (Hunt, Arar, & Larne, 1998; Paterson, 2001b; Thorne, McCormick, & Carty, 1999).

### Implications for Education

#### Client Education

Findings from this study support the notion that adolescents have a significant body of knowledge, both scientific and experiential. It would be useful to consider such knowledge as a valuable resource for others with type 1 diabetes, particularly newly diagnosed individuals or others who might benefit from learning from their peers. Therefore, a model of client education that encompassed peer-led client education programs would acknowledge the expertise of such individuals and also provide a way of using a very valuable resource and source of knowledge (Hunt Joseph, Griffin, Hall, & Doherty Sullivan, 2001; Paterson & Thorne; 2000b). In addition, such a focus would enable nurses and other health care professionals to learn from their clients in a way that would acknowledge and applaud adolescents' knowledge base and their unique perspective.

#### Nursing Education

Although the current study's direct implications for nursing education may be limited, I believe it is crucial for nursing educators and students to recognize adolescents' knowledge and expertise in the context of type 1 diabetes management. Nursing students, nursing educators, and practicing nurses can learn valuable lessons and gain precious insights from individuals living with and managing their chronic illness if they access clients' knowledge and acknowledge and value their expertise.

In an effort to understand what undergraduate students are being taught about the notion of client expertise I attended two undergraduate classes at the University of British Columbia School of Nursing. One class was part of a medical/surgical course and the

topic was diabetes. The second class was part of a pediatric course and the focus was chronic illness. Interestingly, in both classes, professors placed significant emphasis on the knowledge and expertise of those living with and managing chronic illnesses. This was very reassuring given the findings from this study and the literature recommending that practitioners acknowledge clients' perspectives. Such an emphasis could be incorporated into nursing education curricula so that it is universally taught to nursing students from the beginning of their education program.

#### Implications for Research

Given the findings from this study, adolescents' expertise in diabetes management is a credible objective yet it was not clear how participants developed expertise. In addition to defining expertise so that it is of practical use, it would be advantageous for nurses to discover how expertise develops in adolescents. For example, why did Roger appear to have expertise in knowing but not in doing? Is Roger typical of the adolescent diabetes population? If so, why? Or, are the other five participants typical? Are the themes and contexts associated with the five adolescents with expertise congruent with Roger's experience of managing diabetes? My interpretation was that Roger differed significantly from other participants particularly in the individual and social realms. Does this imply that these contexts are associated with expertise and/or its development? These unanswered questions lead to implications for nursing research and knowledge development; in particular, concept analyses to define expertise and empirical studies to explore expertise development. Such work would allow nurses to promote the development of expertise, nurture its existence, and perhaps gain some understanding of why some individuals develop it while others do not.

There is little doubt that the use of a variety of data collection methods facilitated the acquisition of rich data; data that might have remained undisclosed had I used a single method only. Although the nature of this study's inquiry might not appear to be sensitive, the data revealed during the focus group process was potentially so. Because of this, it might be interesting to consider peer-led focus groups as part of the research process. During the focus group, participants disclosed relationships with health care providers that were less than ideal, attitudes of parents that promoted behaviors that were somewhat problematic, and lifestyle issues that had previously been minimized. It is feasible that focus groups are a particularly useful method of data collection for this population and should therefore be considered as an additional means of accessing data when researching adolescents.

### **Conclusion**

In this study, I explored the everyday decision making of adolescents who were nominated as having expertise in their diabetes management. Findings from this study exposed the complexities of participants' lives and revealed that everyday decision making is both an art and a science, both of which are enacted in the social context of adolescents' lives. Within these broad themes of art and science, adolescents' enactment of expert everyday decision making occurred within individual, social, gendered, and socio-political contexts. Although the nature of this small qualitative study precludes generalizations, it enhances our understanding of expertise in decision making in the adolescents in this study. Furthermore, perhaps the findings pave the way for future research and knowledge building in this important and underdeveloped area of chronic illness.

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**THE UNIVERSITY OF BRITISH COLUMBIA**

**APPENDIX A: LETTER OF CONTACT**



School of Nursing  
 T201-2211 Wesbrook Mall  
 Vancouver, B.C. Canada V6T 2B5  
 Tel: (604) 822-7417  
 Fax: (604) 822-7466

**Title of Study:** An interpretive description of how Adolescents with Type 1 Diabetes make everyday decisions.

Date \_\_\_\_\_

Dear \_\_\_\_\_,

My name is Kathy O'Flynn-Magee and I am a registered Nurse and a student in the Master of Science in Nursing program at the University of British Columbia, under the supervision of Dr. Sally Thorne. I am doing a study to find out how adolescents with expertise in their diabetes management make everyday decisions. This study is being carried out to complete my masters thesis and as partial requirement for my masters degree. To do this I would like to talk with adolescents who have been nominated by their health care provider as having expertise in their diabetes self-care decision making. Therefore, people like you are being approached to see if you would be willing to participate in the nomination process. I anticipate that understanding how experienced adolescents make these decisions may assist Health Care Professionals to support and acknowledge their expertise and may facilitate the acquisition of expertise in less experienced individuals.

I am seeking approximately six participants, 3 female and 3 male, whom you consider to have expertise in their diabetes management. Ideally, participants will be between the ages of 15 and 17, live in Vancouver or the Lower Mainland, and be able to speak and understand English. For the purposes of this study, expertise is understood when health care professionals recommend an adolescent as being more skilled than most at diabetes self-care decision making. Expert decision making on the part of the adolescent does not presuppose that the adolescent makes all decisions independently. Rather, it implies that decisions are made in the context of interdependent relationships such as those of family and health care provider.

The study consists of two individual interviews, tape recording by participants of their daily decisions regarding the management of diabetes for a period of one week, and a final group interview with other participants of the research in which the researchers share the findings which result from the study and seek participants' responses to these findings. Each individual interview will last for approximately one hour. The group interview or focus group, scheduled at the end of the research, will also last for approximately one hour to a total of three hours of interview time. It is estimated that the tape recording will require approximately up to 2.5 hours therefore a maximum of 5.5 hours of the participants' time will be required if they decide to participate in this project.

If you are aware of individuals in your care who meets the criteria of this project, please

inform them about the study and ask them if they would like additional information about the research. I will contact you within two weeks of receiving this letter. You will be asked for the names and telephone numbers of individuals who have expressed an interest in the study. I will contact each individual by telephone to provide a description of the study, answer any questions, and invite participation. They will be told that participation is voluntary and that, if they do not wish to participate or if they choose to withdraw from the study, it will not affect the health care they receive.

A copy of the consent form and ethical approval has been appended for your interest. If you have any questions or concerns about my request, please contact me at xxx-xxx or Dr. Sally Thorne at 822-xxxx.

Thank you for consideration of this request.

Sincerely,

Kathy O'Flynn-Magee

**APPENDIX B: PARTICIPANT INFORMATION LETTER**

School of Nursing  
T201-2211 Wesbrook Mall  
Vancouver, B.C. Canada V6T 2B5  
Tel: (604) 822-7417  
Fax: (604) 822-7466

Hi, my name is Kathy O'Flynn-Magee and I am a registered Nurse and a student in the Master of Science in Nursing program at the University of British Columia, under the supervision of Dr.Sally Thorne. I am doing a study to find out how adolescents with expertise in their diabetes management make everyday decisions. This study is being carried out to complete my masters thesis and as partial requirement for my masters degree. To do this I would like to talk with adolescents who have been nominated by their health care provider as being more skilled than most at diabetes self-care decision making. Therefore, people like you are being approached to see if you would be willing to participate in the study.

The study consists of two individual interviews with me, tape recording by you of your daily decisions regarding diabetes management for a period of one week at some point in between the two interviews (" Think-Aloud Technique "), and a final group interview with other adolescents who have participated in the study. The focus of the group interview is to share the findings which result from the study and to ask you if you agree with these findings.

As a participant in this study, I will ask you to talk to me about having Type 1 diabetes and about how you make decisions every day. I expect the interviews will last for about an hour but yours may be shorter or longer depending on what you choose to tell me. The focus group, scheduled at the end of the research, will also last approximately an hour. It is difficult to estimate exactly how long the Think-Aloud will take as it depends on how often you record your thoughts over the week. Other researchers using this method have estimated approximately 2.5 hours for this activity therefore a total of approximately 5.5 hours of your time will be required if you decide to participate in this project.

To allow me to remember the interviews and focus group, I will be audio taping the interviews. These audiotapes will be transcribed by Kathy O'Flynn-Magee or by a typist. The tape recording of the interview(s) and transcript(s) may be saved for future (secondary) analysis by the researcher for a period of five years following completion of this study. At this time, all the audiotapes will be destroyed. You may ask me to erase any portion of the tape at any time. All the information you provide will be held in strict confidence and all the identifying information will be removed. I will identify the information by code numbers/pseudonyms, not names or initials, and the data will be kept secure. You may choose a pseudonym at the beginning of the study if you wish. You are under no obligation to participate in the study, and if you choose not to participate in or to withdraw from the study at any time, your current and/or future medical and nursing care will not be affected.

Understanding how experienced adolescents make self-care decisions may help nurses and

## APPENDIX C: PARENT INFORMATION LETTER



School of Nursing  
T201-2211 Wesbrook Mall  
Vancouver, B.C. Canada V6T 2B5  
Tel: (604) 822-7417  
Fax: (604) 822-7466

My name is Kathy O'Flynn-Magee and I am a registered Nurse and a student in the Master of Science in Nursing program at the University of British Columbia, under the supervision of Dr.Sally Thorne. I am doing a study to find out how adolescents with expertise in their diabetes management make everyday decisions. This study is being carried out to complete my masters thesis and as partial requirement for my masters degree. To do this I would like to talk with adolescents who have been nominated by their health care provider as being more skilled than most at diabetes self-care decision making. Therefore, people like \_\_\_\_\_ are being approached to see if s/he would be willing to participate in the study.

The study consists of two individual interviews with me, tape recording by \_\_\_\_\_ of her/his daily decisions regarding diabetes management for a period of one week at some point in between the two interviews ("Think-Aloud Technique"), and a final group interview with other adolescents who have participated in the study. The focus of the group interview is to share the findings which result from the study and to ask \_\_\_\_\_ if s/he agrees with these findings.

As a participant in this study, I will ask \_\_\_\_\_ to talk to me about having Type 1 diabetes and about how s/he makes decisions every day. I expect the interviews will last for about an hour but \_\_\_\_\_'s may be shorter or longer depending on what s/he choose to tell me. The focus group, scheduled at the end of the research, will also last approximately an hour. It is difficult to estimate exactly how long the Think-Aloud will take as it depends on how often \_\_\_\_\_ records her/his thoughts over the week. Other researchers using this method have estimated approximately 2.5 hours for this activity therefore a total of approximately 5.5 hours of \_\_\_\_\_'s time will be required if s/he decides to participate in this project.

To allow me to remember the interviews and focus group, I will be audio taping the interviews. These audiotapes will be transcribed by Kathy O'Flynn-Magee or by a typist. The tape recording of the interview(s) and transcript(s) may be saved for future (secondary) analysis by the researcher for a period of five years following completion of this study. At this time, all the audiotapes will be destroyed. \_\_\_\_\_ may ask me to erase any portion of the tape at any time. All the information \_\_\_\_\_ provides will be held in strict confidence and all the identifying information will be removed. I will identify the information by code numbers/pseudonyms, not names or initials, and the data will be kept secure. \_\_\_\_\_ may choose a pseudonym at the beginning of the study if s/he wishes. \_\_\_\_\_ is under no obligation to participate in the study, and if s/he chooses not to participate in or to withdraw from the study at any time, her/his current and/or future medical and nursing care will not be affected.

Understanding how experienced adolescents make self-care decisions may help nurses and other health care professionals to support and acknowledge their expertise and may help

I consent to participate in this study.

---

Participant Signature

Date

---

Witness Signature

Date

I consent /do not consent to \_\_\_\_\_ ( participant's name) participating in this study.

---

Parent Signature

Date

---

Witness Signature

Date

## APPENDIX F: SAMPLE INTERVIEW QUESTIONS

### Initial Interview

I will begin the interview with a general question such as:

Tell me a little about yourself, including your age, current grade at school, family members etc.  
 What is it like for you as a young person having Type 1 diabetes?  
 How would you describe your experience of living with/having diabetes?  
 How has your life changed since your diagnosis of diabetes?  
 Please tell me about when you found out you had diabetes  
 Can you tell me about the decisions you make around your diabetes management ?  
 Can you describe what a typical day is like for you ?  
 Can you tell me more about.....

I may end the interview with questions such as :

Is there anything else you'd like to tell me ?  
 Is there anything you would like to ask me ?  
 How has the interview been for you ?

### Second Interview ( following Think-Aloud )

Questions will be based on information collected in the initial interviews, and/or the Think-Aloud statements.

An example might be:

Have you had any further thoughts about ....?  
 You talked about \_\_\_\_\_ in your Think-Aloud so can you tell me a little bit more about that ?  
 Other researchers have found \_\_\_\_\_. Is this an issue for you ?

### Focus Group Interview at the completion of research

I will share my findings with the participants and ask for clarification, if necessary. Examples of questions are:

Do you agree with these findings ?.....In what way?.....Were you surprised?.....In what way?  
 Is there anything I missed ?  
 How has the research process/ experience been for you ?  
 Are there aspects of the research process that were helpful/unhelpful?  
 Do you have any questions for me?

**APPENDIX G: DEMOGRAPHIC DATA FORM**

Pseudonym \_\_\_\_\_

Age \_\_\_\_\_

Sex \_\_\_\_\_

Lives with ? \_\_\_\_\_

Siblings: ages ? \_\_\_\_\_

Currently attending High School ? \_\_\_\_\_

Grade? \_\_\_\_\_

When was your diabetes diagnosed? \_\_\_\_\_

## APPENDIX H: THINK-ALOUD GUIDELINES

During the Think-Aloud period, please "talk aloud" your thoughts and feelings around your decisions. In the beginning, you may feel rather awkward doing this. However, if you keep doing it, it will probably stop causing you concern.

I am interested in everything to do with how you make decisions around your diabetes. Nothing you say will be trivial or irrelevant to me so please share whatever comes to mind as you make decisions throughout the day. It is really helpful to me if you 'talk aloud' at the same time as you are actually making decisions. I understand that this may not always be possible. If this happens, you can record your thoughts as soon as possible after making your decision.

When you make a decision, please describe it in as much detail as possible. Then, try to record your thoughts and feelings around the following:

How did I decide what to do ?

Why did I do that ?

Did I talk to anyone about what to do ?

Why ?

Why not ?

Have I been in this situation before ?

If so, did it help me to decide ?

Did I feel ok about my decision ?

Did I have a hard time trying to decide ?

Why ?

Why not ?

Would I make the same decision again ?

Was it the kind of decision I have never had to make before ?

Do I think it was a "good" decision ? or not ?

Did anyone else ( eg. friends, parents ) influence my choice ?

If you have any questions before, during, or after the Think-Aloud period, please call me at xxx-xxx. Thank you.

Sincerely,

Kathy O'Flynn-Magee.