

TAKING CONTROL OF DIABETES:
CHILD AND ADOLESCENT PERSPECTIVES ON THE EVOLUTION
OF SELF-CARE

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Taking Control of Diabetes:
Child and Adolescent Perspectives on the Evolution of Self-care

Noshin Khan 2012

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Early Childhood Studies
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Abstract

This qualitative study employed an ethnographic approach to explore perspectives of children and adolescents on diabetes self-care. Their knowledge of diabetes and feelings about having the disease was also addressed. Rooted in the new sociological approach that acknowledges children's right to participate in issues that concern them, forty eight paediatric patients between the ages of five and eighteen years participated in individual interviews. Participants were recruited from a diabetes outpatient clinic within the largest paediatric hospital in Canada. Data were coded using McCracken's (1988) method of analysis. This paper presents a focused analysis of three major themes: self-care, knowledge and feelings. In-depth analyses of these integrated themes provided a rich understanding of how children and adolescents with diabetes come to accept their disease and how the process of self-care evolves over time. Despite the emotional challenges and complexity of managing diabetes, children and adolescents spoke of a resolve and readiness to obtain more knowledge about their disease. This paper describes the process of diabetes self-care from the perspectives of children and adolescents and offers suggestions for clinical practice and future research.

Keywords: Diabetes, Type 1 Diabetes, Adolescents, Children, Self-care, child participation

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Dedication

To my wonderful father, who had faith in me and believed that I could achieve the ultimate.

He made me believe that I could accomplish anything through perseverance.

“You may encounter many defeats, but you must not be defeated. In fact, it may be necessary to encounter the defeats, so you can know who you are, what you can rise from, how you can still come out of it.”

Maya Angelou

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Introduction

Type 1 diabetes is a chronic condition with long and short-term consequences for children and adolescents, their families and society. It is described as a “chronic, debilitating and costly disease associated with major complications that pose severe risks for families, countries and the entire world” (United Nations (UN) General Assembly Resolution 61/225). Today approximately 1.9 billion children below the age of 14 years have diabetes, out of which around 490,000 have Type 1 diabetes (Diabetes Atlas, 2011; Public Health Agency of Canada, 2011). Canada has one of the highest incidence rates of type 1 diabetes in children under the age of 14 years (Juvenile Diabetes Research Fund [JDRF], 2012). “The incidence rate of type 1 diabetes in Canadian children and adolescents is rising by three to five per cent and the greatest rise occurs in five to nine year olds” (JDRF, 2012).

Type 1 insulin-dependent diabetes, a metabolic disorder and one of the most common chronic illnesses in children (IDF, 2011; JDRF, 2011), is an autoimmune disorder in which the body’s immune system attacks the insulin producing beta cells of the pancreas (IDF, 2011; JDRF, 2011; Kaufman, Gallivan & Warren-Boulton, 2009). The impaired functioning of the pancreas results in a lack of production of insulin, a hormone which metabolizes carbohydrates and turns sugar into energy (JDRF, 2012). The inability to produce insulin and metabolize sugar can result in severe consequences for those with diabetes (American Diabetes Association [ADA], 2012; Kaufman, et al, 2009; Patton, Dolan, Henry & Powers, 2008; Silverstein et al., 2005).

Children and adolescents with Type 1 diabetes must manage a multi-component regimen comprising of blood glucose monitoring (BGM), insulin injections, diet modification and

regular exercise (Chisholm et al. 2011; Daneman, Frank & Perlman, 2002; Fritsch & Olshan, 2011; Helgeson & Palladino, 2012; Schilling, Grey & Knafl, 2002). Adherence to this regimen is essential to maintaining health and minimizing the risk of complications (Chisholm et al. 2011; Kaufman et al., 2009). In the short term, if blood sugar levels drop dangerously low and are not recognized, they can result in seizures, coma or even death (Patton et al., 2008; Silverstein et al., 2005). Moreover, if Type 1 diabetes is not managed well over time, it can cause complications such as heart and kidney disease, retinopathy, hypertension, and nerve damage and in some cases limb amputation (ADA, 2012; Kaufman, et al, 2009; Patton et al, 2008; Silverstein et al., 2005). Hence, regardless of what other activities and events may be happening, children and adolescents, and their families must adhere to the regimen (Fritsch & Olshan, 2011; Schilling, et al., 2002).

Purpose of Study

The purpose of this study was to gain understanding of how children and adolescents with Type 1 diabetes understand their illness and the processes associated with self-care. Management of Type 1 diabetes involves several lifestyle adjustments that can be difficult for children and adolescents. As Alderson, Sutcliffe, and Curtis (2006) illuminate, daily management of diabetes clearly reflects the intellectual and social competence of children because diabetes management is about “controlling sugar, a key currency and symbol of childhood” (p.26). Further they state,

In many cultures, confectionery is used to signify affection, popularity, and inclusion; to mark passing time (for example, birthday cakes); to celebrate holidays (for example, chocolate Easter eggs); to reward, bribe, or barter; and (by withdrawal) to threaten and punish. Against this dominant sugar economy, children with diabetes have to avoid sugar

and cope skillfully with being different from their friends without losing friendship and respect (p.26).

In view of the challenges faced by children and adolescents with Type 1 diabetes, this study examines how they experience life with diabetes and their involvement in self-care. The study was conducted in 2008 at a large, paediatric hospital in Canada.

The following research questions were addressed;

1. How do children and adolescents with Type 1 diabetes understand their disease?
2. How do children and adolescents with Type 1 diabetes perceive their involvement in managing the disease?
3. What types of self-care activities are children and adolescents with Type 1 diabetes involved in?
4. What factors do children and adolescents with Type 1 diabetes identify as important in eliciting, sustaining or inhibiting self-care?
5. How does participation in self-care evolve over time?

Data was collected and coded by Dr. Koller and her research assistant. In fulfillment of my Masters degree, I reviewed all the interview transcripts and re-coded several categories of the data in order to derive a central narrative to the question of how self-care evolves from the perspectives of youth with diabetes. The central narrative or meaning of the data is based on the three major themes identified in the data: self-care, knowledge and feelings. This paper presents these findings from an original study where children and adolescent with Type 1 diabetes were interviewed. Finally, this paper also discusses these findings in reference to clinical practice.

Theoretical Framework

Children's right to participate in research and make decisions concerning their well-being is well acknowledged in research and practice (Alderson, 2008). Inclusion of children in the research process is based on two parallel initiatives; the global recognition of children rights (Morrow, 2008) and the emergence of the new sociological approach to childhood (Danby & Farrell 2004; Einarsdottir, 2007). The United Nation Convention on the Rights of the Child (UNCRC) (1989) acknowledges children's right to partake in decisions affecting their lives and to communicate their views. Article 12 of the UNCRC (1989) states that "a child who is capable of forming his or her own view should have the right to express these views freely on all matters affecting the child and that those views should be given weight in accordance with age and maturity."

The new sociological approach provides support to the UNCRC legislation by viewing childhood as a social construct and children as social actors (Einarsdottir, 2007) who are "competent interpreters of their everyday worlds" (Danby & Farrell, 2004, p.35). Jens Qvortrup, regarded as the "founding father" of the new sociology of childhood (Morrow, 2008) stresses children's individualism, autonomy, capacity and competence (Einarsdottir, 2007; James & Prout, 1990). Childhood and children are hence considered worthy of inquiry in their own right, separate from their parents (Corsaro, 1997; Christensen & James, 2000; Einarsdottir, 2007; James & Prout, 1990; Lloyd-Smith & Tarr, 2000; O'Kane 2000; Qvortrup, 2004).

In the last twenty years, researchers have come to realize that children's experiences are unique and their interpretation of those experiences novel. In order to learn more about how children experience events and in turn how they interpret them, researchers must focus on asking them directly rather than their parents or professionals caring for them (Franck & Callery, 2004;

Twycross, 2012; Watson, Abbot & Townsley, 2006). Researchers have acknowledged the importance of understanding children's perspectives because their perspectives may "differ from, and be more sophisticated than, accounts based on what adults think children think" (Balén et al, 2006, p.31). Even though many researchers have authenticated their trust in children and adolescents by including their views and opinions in a growing body of literature, they continue to debate related methodological and ethical issues. (Balén et al, 2006; Corsaro & Molinari, 2000; Danby & Farrell 2004; Einarsdottir, 2007; Hallett, 2000; Mayall, 2000; O'Kane, 2000; Punch, 2002; Twycross, 2012).

An important methodological and ethical issue is whether to consider research with children same as, or different to, research with adults (Punch, 2002). Punch (2002) argues that it is not appropriate to conceptualize research with children and adults as two extremes; the same or different.

Instead it should be seen as on a continuum where the way that research with children is perceived moves back and forth along a continuum according to a variety of factors: individual children, the questions asked, the research context, whether they are younger or older children and the researcher's own attitudes and behaviour. (Punch, 2002, p.338)

Within paediatrics, a growing body of literature emphasizes children's capacity to make informed decision regarding their health (Alderson et al., 2006; Moore & Kirk, 2010). Moreover, children four years and older who suffer from a chronic illness or have a disability have shown great competence in making decisions about their healthcare (Alderson, et al., 2006; Moore & Kirk, 2010). Alderson (2002), in her studies on children's ability to understand and make decisions, explored children's perspectives on topics such as consent to surgery. Her

research illuminated children's ability to exercise their rights and make decisions concerning their well-being by themselves and for themselves.

More specifically, Alderson et al. (2012) in their study on diabetes care found that children often have a better capacity to understand and undertake healthcare decisions than is recognized in bioethics. They conclude protecting children with Type 1 diabetes from their disease means getting them as involved as possible in managing their condition. They explain, by helping children and adolescents understand diabetes and take responsibility for self-care, adults can facilitate them to navigate through a multitude of daily decisions that characterize diabetes care.

An important component of educating children about diabetes involves effective communication processes. For example, the American Academy of Paediatrics, (AAP) (2008) highlights the importance of communicating with children and their families. According to the AAP, two types of patient needs must be addressed during the medical interviews; cognitive which serve the need to understand diabetes, ask questions and give information, and affective which serve the emotional need and include showing respect, concern, and compassion for children and adolescents (Leveton, 2008). By promoting self-care through education and psychosocial support, better management of diabetes in the paediatric population is an expected outcome (Lange, Sassmann, Schutz, Kordonouri & Danne, 2007).

In summary, the theoretical framework for this study is rooted in the new sociology of childhood which views children as competent interpreters of their worlds with participation rights. In contrast, a review of the research on children's and adolescents' experiences with diabetes is predominantly conceptualized within a developmental framework where age and

developmental level inform the research methods and clinical practice recommendations. For these reasons, both frameworks are reflected in this paper.

Scope of the Literature Review

Given the complexity of the condition and the substantial lifestyle adjustments required in managing diabetes, several concepts associated with self-care in diabetes were searched in the literature. This literature review includes publications from peer-reviewed academic journals between 2002 and 2012. Publications were searched on the following databases; Proquest Research Library, Proquest Nursing, Academic Search Premier, PubMed, Medline, Psychinfo, CINAHL and Educational Research Information Clearinghouse (ERIC). Key words used in the search consisted of: diabetes, type 1 diabetes, diabetes treatment, children, adolescents, teenagers, self-care, knowledge, participation, management, social support, healthcare practitioners, physicians, nurses, parents, school, peers and teachers. A table outlining definitions of key terms are included under Appendix A.

Literature Review

A review of literature revealed a dearth of information on the perceptions of younger children, however substantial literature documenting adolescent perceptions of diabetes and its management was found in the body of literature. These perspectives are integral to the development of strategies that foster positive diabetes related behaviours (Herrman, 2006).

Self-Care

The term self-care is widely used in paediatric diabetes literature, yet there is no universal definition of self-care (Schilling et al., 2002). Moreover, there is a lack of differentiation in expectations associated with self-care between children, adolescents and adults (Schilling et al., 2002). The ambiguity in the meaning of self-care and what it entails creates

several difficulties; it makes it challenging for children and adolescents to understand what it means, and when and how much involvement in self-care is appropriate or required of them (Schilling et al., 2002).

Within the context of self-care, age and developmental levels are powerful contextual variables (Schilling et al. 2002). In particular, the quality and degree of self-care is affected by child related factors such as age, developmental level, maturity, temperament and personality of children and adolescents (Herrman, 2006; Roper et al, 2009; Stallwood, 2005). A number of studies indicate adolescents are less competent and consistent in self-care when compared to younger children (Streisand & Mednick, 2006; Dashiff, McCaleb & Cull, 2006; Karlsson, Arman & Wikblad, 2008).

More specifically, parents of younger children carry more burden of managing their children's diabetes (Lowes, 2008) compared to parents of school age children and adolescents (Lowes, 2008). Research has shown that despite efforts to encourage young children's involvement in their care, the burden of adjusting and making lifestyle changes falls primarily on the parents (Dovey- Pearce et al. 2005; Lowes, 2008). Even the most involved children with diabetes often struggle with the daily demands of caring for diabetes (Fritsch & Olshan, 2011). However difficult it may be for young children to take on many self-care activities, it is imperative to gradually involve them in self-care. Over time, with practice young children will become more adept at self-care (Dovey- Pearce et al, 2005; Lowes, 2008). Accordingly, competent self-care essentially promotes management of diabetes, which in turn fosters good health for the future (Dovey- Pearce et al. 2005; Lowes, 2008).

Even though young children require adults to carry out or supervise activities such as checking blood sugar levels and injecting insulin (Stallwood, 2005), children may be given the

opportunity to choose which finger to prick and where to inject the insulin (Chisholm et al., 2011). Chisholm et al. (2011), in their study with children between the ages of 2 and 8 years, suggest that treatment adherence and health are augmented when children are presented with age appropriate and developmentally sensitive opportunities to participate in diabetes care. Lowes (2008) proposes that children as young as five years of age are able to understand and follow simple explanations especially if presented through a pictorial format.

As children transition from childhood into early adolescence they need and want greater autonomy (Karlsson, et al., 2008). Karlsson et al. (2008) interviewed 32 adolescents with diabetes about their individual experiences of self-care. The over-riding theme that emerged was that adolescents were “hovering between individual action and support of others” (p. 562). While teenagers are moving towards autonomy, parents and caregivers accustomed to being in control can find it difficult to relinquish control to their children (Ivey Wright & Dashiff, 2009; Karlsson et al. 2008; Leonard, Garwick and Adwan, 2005). This dynamic often results in a power struggle between adolescents and parents (Ivey et al., 2009; Karlsson et al, 2006; Leonard et al., 2005).

Ivey et al. (2009) in their study with 11 to 15 year olds found that the adolescents were frustrated during the transition period from parent care to self-care. On the other hand, parents were fearful and apprehensive about giving up control because adolescence has been associated with a period of poor glycemic control (Gaston, Cottrell & Fullen, 2011). Gaston et al. (2011) in their study with fifty-five, 12 to 16 year olds found that adolescents and parents had very different ideas about the severity of the condition and necessity to comply with the regimen. “Parents believed diabetes to be more chronic, to have a more negative impact, pose more of a threat to adolescents’ health and believed more strongly in the effectiveness of treatment than did adolescents” (Gaston et al., 2011, p. 513). Furthermore, Karlsson et al. (2006) who interviewed

32 adolescents in a Swedish children's hospital to explore their experiences of living with diabetes found that adolescents wanted autonomy in managing their diabetes while retaining family support. The adolescents in this study valued making choices and decision about how to manage their condition and learn from their mistakes. The results reinforced the significance of experiential knowledge as key to the successful management of diabetes.

Knowledge of Diabetes

The degree of diabetes knowledge is a variable closely associated with the level of self-care. As described by the International Society for Paediatric and Adolescent Diabetes (ISPAD) Clinical Practice Consensus Guidelines 2006-2007, "education is the keystone of diabetes care and structured self-management education is the key to a successful outcome" (Swift, 2007, p.103). The ISPAD consensus guidelines indicate that diabetes education programmes should be carefully structured such that they address the needs of individuals with diabetes, and their families and caregivers. In other words, children, adolescents, their parents and caregivers should have easy access to knowledge and information on diabetes (ISPAD, 2007).

Research, however, has shown that children and adolescents have limited knowledge about their diabetes and its management (Chaney et al, 2010; Roper et al., 2009). Roper et al., (2009) conducted one of the few studies examining children's knowledge of diabetes. They interviewed 58 children and adolescents with diabetes in order to assess what they knew about diabetes and whether they wanted to know more. They found that although children and adolescents had some basic knowledge about diabetes care and the physiology of their condition, they expressed the desire to have more knowledge about physical health and what to do when, and if, they had a reaction to insulin. Therefore, even though they knew about the short and long term consequences of diabetes, they wanted to know more. In particular, some were concerned

about the long-term consequences of mismanagement that could result in limb amputations or death. Roper et al. (2009) emphasizes the importance of evaluating the knowledge held by children and adolescents with diabetes in order to ensure an accurate and developmentally-appropriate understanding of the disease.

Diabetes education should be sensitive to the changing needs of young people and their families as they experience different stages of life (Swift, 2007; Swift, 2000). In a study by Chaney et al. (2010), twenty one 13 to 18 year olds were interviewed regarding how diabetes education programmes should be structured. Participants expressed the need for educational programmes that were tailored to individual needs. The study concluded that adolescents favoured programmes that were “short in duration, practical in nature, positive in outlook, and relevant to daily life” (p.216).

In contrast, Murphy, Rayman and Skinner (2006) are critical of relying solely on diabetes education for better health outcomes. Based on their review of 27 articles published between 2000 and 2005, they concluded there was insufficient evidence to support the effectiveness of any particular diabetes educational programme. According to Murphy et al. (2006) “education appears to be most effective when integrated into routine care, when parental involvement is encouraged, and when adolescent self-efficacy is promoted. It may be that education alone has only modest effects at best, and should be considered in addition to intensive insulin or behavioural interventions” (p.940). Furthermore, they state that educational programmes, which may seem to work well in one setting, may not be applicable in others.

In many ways, education remains fundamental to mastering diabetes care; especially in the case of young children (Howe, Ratcliffe, Tuttle, Dougherty & Lipman, 2011; Howells, 2002; Rzeszut, 2011; Stallwood, 2005; Swift 2007). “Adequate age appropriate diabetes knowledge

and skills are essential to the success of self and parental care” (Howells, 2002, p.69). More specifically, diabetes education and knowledge of non-compliance related complications can have positive effects on general management of the condition (Hoey, et al., 2001; Karaguzel, Bircan, Erisir & Bundul, 2005; Roper et al. 2009). In summary, education that culminates in knowledge plays a pivotal role in the promotion of diabetes self-care (Howe et al. 2011; Rzeszut, 2011; Stallwood, 2005; Swift 2007).

Feelings about Diabetes

Research has shown that children and adolescents with diabetes experience a range of negative emotions at diagnosis, which can continue for a prolonged period of time. According to Cammarata et al. (2009) psychological support beginning at the time of diagnosis can have a positive influence on patient outcomes. Children and adolescents with Type 1 diabetes experience several emotions such as sadness, guilt, anxiety, anger, depression and social withdrawal at diagnosis and in their daily live (Cammarata et al. 2009). Acceptance of illness, initial adjustment and school and family stress play an important role in predicting the psychosocial wellbeing of children and adolescents with diabetes. Therefore, psychosocial wellbeing has a strong influence on children’s and adolescents’ quality of life.

Even though there is limited literature on the emotional effect of diabetes on younger children (Herrman, 2006; Stallwood, 2005), needle anxiety and associated phobias are a major source of emotional upheaval (Howe, et al., 2011; Rzeszut, 2011). Young children may experience stress as a result of the numerous needle pricks for checking blood sugar and injecting insulin on a daily basis (Howe, et al., 2011; Rzeszut, 2011). Psychosocial interventions such as medical play with syringes and glucose monitoring allow children to become accustomed

to the needles. The use of interactive materials has proven to be extremely effective with younger children (Koller, 2006; Koller, 2008, EPB statement on play).

In contrast, there is a body of literature associated with the psychosocial well-being of adolescents with diabetes. Adolescence is regarded as a particularly difficult stage of development because it represents a time of hormonal changes (de Wit et al., 2008). Research has documented the influence of hormonal changes on attitudes and behaviours (de Wit et al., 2008). For example, Faulkner (2003) examined life satisfaction in sixty-nine adolescents with diabetes and seventy healthy adolescents. Adolescents with diabetes were found to have less life satisfaction and expressed more concern about their health. The study also noted differences between older and younger adolescents, with older adolescents expressing a lower life satisfaction level and more health concerns than their younger counterparts.

Furthermore, Dovey- Pearce, et al., (2005) in a qualitative study conducted semi-structured interviews and focus groups with 19 young adults (16-25 years). They asked the adolescents to think back and recall their emotional needs during early adolescence. Early adolescence was defined as the ages between 11 and 15 years. Reflecting back on their needs, the participants expressed a desire for greater social and emotional support. Taken together, the studies on the psychosocial impact of diabetes on adolescents (Dovey- Pearce et al. 2005; Faulkner, 2003) illuminate the significant benefits associated with providing adequate psychosocial support.

Methods

Qualitative methods address how people perceive or experience situations. They are often employed in health related research (Boyd, 2001; Britten, 2011; Broussard, 2006) because they provide rich and dense data about complex issues (Boyd, 2001; Britten, 2011; Broussard, 2006). For example, qualitative researchers interview and observe their participants to gain a deeper understanding of intricate details about feelings, thought process and knowledge, and emotion that are difficult to measure using other methods (Britten, 2011; Broussard, 2006). Exploring children's and adolescents' experiences about illness allows qualitative researchers to capture a multifaceted view of their understanding and knowledge (Nabors Lehmkuhl, Christos, & Andreone, 2003). In this study an approach that allows the participants to tell their stories (Britten, 2011; Broussard, 2006) was deemed suitable because self-care, knowledge and feelings in the paediatric population are interrelated and complex concepts. For children and adolescents to discuss experiences from their daily lives, it is important to employ research methods that provide the opportunity for informal reflexivity and dialogue (Christensen, 2004). Research practices that encourage reflexivity and dialogue allow researchers to enter into children's "culture of communication" (Christensen, 2004, p. 165). For these reasons, an ethnographic interpretative perspective guided the research methods.

Ethnography is a distinct type of qualitative research where researchers are in close social interaction with participants for an extended period of time (Christensen, 2004). The goal of ethnographic research is to gain an in-depth understanding of people, cultures, religions and ethnic groups from them, as opposed to learning about them. Researchers who employ ethnographic methods immerse themselves in the lives of the participants while the participants remain in close proximity to their own environment (Britten, 2011; Broussard, 2006).

The researchers in this study wanted to gain an understanding of how children and adolescents perceive their experiences related to life with diabetes. Children and adolescents with diabetes are a distinct cultural group that share many commonalities, often not shared by any other group or culture. The diabetes clinic was deemed an appropriate context for this study because it was a common, familiar and a comfortable environment for most participants. By interviewing the children in the clinic, the daily experience of having diabetes is at the forefront of their ability to discuss the ongoing and pervasive demands of the disease. In summary, through close and intense communication with the paediatric diabetic population at the outpatient clinic, the researchers were able to discuss complex diabetes-related issues with children and adolescents.

McCracken (1988) offers one example of an ethnographic approach through the use of the 'long interview method' (p.7). According to McCracken, "the purpose of qualitative interview is not to discover how many and what kinds of people share a certain characteristic. It is to gain access to cultural categories and assumptions according to which one culture construes the world" (1988, p.17). In this study, the long interview method was suitable for exploring diabetes related issues with children and adolescents who held a variety of perspectives and life experiences.

Participants

This ethnographic study employed a participatory approach. In a participatory approach, children can participate in developing research questions and data collection methods, provide insight regarding children's preferences and can participate in analyzing findings (Alderson, 2000). In this study, the participatory approach included children's perspectives regarding the research design. As a collaborator on the study, the Children's Council at the Hospital for Sick

Children (Sick Kids) provided feedback on proposed methods of recruitment and data collection. The Children's Council comprises ten children between the ages of 8 and 18 representing various medical specialities in the hospital. Their mandate is to provide advice from a child's perspective, to act as a resource for hospital staff and to advocate for children's health. Initial feedback from the Children's Council at Sick Kids was incorporated into the research design. For example, suggestions were given on how to describe the study to participants, as well as recommendations for interview questions. In addition, a small group of children and adolescents with diabetes from the outpatient clinic at Sick Kids were asked to review the interview questions prior to study recruitment. The participatory approach required a careful balance, as there are "inescapable power disparities between child participants and adult researchers" (Hunleth, 2011, p.82). Therefore, the expectations for children's participation were carefully examined because children and adolescents have busy lives with school and managing their diabetes.

Sample

A cross-sectional, purposive sample of children and adolescents with Type1 diabetes were recruited. To ensure a variety of perspectives, a mixed gender, stratified sample of 48 participants between the ages of 5 to 8 (n=16), 9 to 12 (n=15) and 13 to 18 (n=17) from the diabetes outpatient clinic at Sick Kids in Toronto, Ontario comprised the sample. Justification for the age group stratification is based on developmental research that cites evolving abilities for abstract thought. These groups were chosen to capture specific developmental stages (cognitive and social emotional) as described by noted theorists Piaget (1955) and Erikson (1959) respectively.

In regard to sample size, purposive samples typically rely on the concept of ‘saturation,’ or the point at which no new information or themes are observed in the data (Creswell, 2009). Studies have validated that saturation normally occurs within the first 10 interviews, although basic elements for meta-themes can emerge as early as six interviews (Cresswell, 2009). In this study, saturation was aimed at 30 interviews (10 per age group). However, in order to ensure adequate saturation, 15 participants per age group were recruited. In addition, to account for gender issues, efforts were made to recruit similar number of boys and girls within each age group.

In addition, the composition of participants was carefully examined in terms of patient A1C levels. According to the Canadian Diabetes Association (2012) A1C is a blood test that reflects a person average blood sugar over the preceding three months. All participants, in this study had average A1C levels, which meant that study participants were representative of an average level of adherence within the outpatient population.

Recruitment

The outpatient clinic at Sick Kids serves approximately 1000 children with Type 1 diabetes over an average of three months. Families from Ontario region are included in this population as well as families from a wide range of cultural backgrounds. The diabetes outpatient clinic provided the context upon which a multi-cultural, mixed gender and multi-age sample could be accessed. A full ethical review was conducted prior to commencement of the study.

The research team consisted of a research assistant, physician, clinical nurse manager, social worker and child life specialist. Members of the research team helped identify suitable children and adolescents from the clinic appointment lists. Once potential participants were

identified, the research assistant followed up with the clinical nurse manager to discuss capacity to consent and possible recruitment. As participants were identified, the research assistant contacted families to provide further information about the study and consent procedures. Appropriate consents and assents were obtained from children.

Although there is no specified age of consent in Ontario, common practice dictates that parents are made aware of the study and can provide consent on behalf of their children (Twycross, 2012). In this study, children under the age of 14 years gave assent and older participants completed consent forms. Parents and children were told that participation in the study was voluntary and that refusal to participate would not affect their care. Although participants did not receive monetary benefits from participating, they were offered gift certificates (e.g., movie pass, small gift) as a token of appreciation. They were also reimbursed for parking or public transit.

Inclusion criteria

1. Children and adolescents who had been diagnosed with Type 1 diabetes for one year or more. Ensuring a level of adjustment to the disease has been noted as important criteria for sample inclusion in other studies (Graue, Wentzel-Larsen, Hanestad, & Sovik 2003; Shroff-Pendley et al., 2002; Wennick & Hallstrom, 2007)
2. Children and adolescents without a mental health issue or other health issues in addition to diabetes. With the exception of well-controlled hypothyroidism, children with additional illnesses such as asthma and celiac disease were excluded.
3. Children and adolescents who spoke and understood English. Clinical nurse educator to identify participants who spoke English.

Finally, participants were recruited on the basis of the above criteria and not on the degree of the perceived compliance.

Data collection

There were two forms of data collection: 1) demographic information and 2) semi-structured interviews. Following consent for both forms of data collection, demographic information was collected. Demographic information included age, gender, number of family members, cultural background, developmental issues (i.e. cognitive delays) and age at which diabetes was diagnosed.

The main source of data comprised individual interviews. The interviews were conducted at the diabetes outpatient clinic at Sick Kids and in a few cases, at the child's home. Five interviews were conducted in the participant's home, while the remaining interviews occurred in the outpatient clinic. By using McCracken's (1988) long interview method, participants had the latitude to convey experiences and perceived needs relative to their developmental level. For this reason two separate interview guides were designed; one for the younger children (5-8 years) and a second for older participants (9-12, 13-18 years). The methods used in the study maintained an important balance between adhering to individual developmental needs and addressing common and salient issues. Although there were two separate interview guides (Appendix B and Appendix C), each schedule included the same type of prompts or topic areas. According to McCracken, these prompts can be well designed questions, which ensure that the investigator covers all the terrain in the same order for each respondent. Prior to conducting interviews, the research assistant was given training in interviewing techniques. This process was achieved through observing the principal investigator conduct interviews and providing supervisory feedback after listening to audio taped interviews by the research assistant.

Child Interviews

In the case of younger children (5 to 8 years), parents were asked to provide demographic information prior to interviews. For children between the ages of 5 and 8, a mix of techniques was used based on their suitability for one to one interviews. For example, opportunities to engage in medical play (playing with real and toy equipment including syringes and blood glucose monitors) along with viewing picture books of children in hospital helped engage young participants in the interview process. Feeling faces (Hall, Kaduson, Schaeffer 2002; Pons, Lawson, Harris, & de Rosnay, 2003) and other similar scales were also introduced as visual aids when discussing emotions associated with having diabetes.

These techniques alongside straight forward questioning are supported in the literature. These combined methods serve to make interviews fun and interesting for young people while being useful in generating relevant data (Christensen & James, 2000; Docherty & Sandelowski, 1999; Punch, 2002). Further support is provided by Negro and Walpow (2004) who acknowledge that the use of props increases the volume of information that young children can provide. Physical props may serve two functions; cues for memory retrieval and aid to communicate complex and emotionally challenging information that may be difficult for young children to verbalize (Negro & Wolpow, 2004).

School-Age and Adolescent Interviews

Semi-structured questions addressed the following areas: involvement in self-care and decision making, understanding of diabetes, and feelings about having diabetes. Participants were asked to describe their involvement in self-care and explain what made it possible and/or challenging. Questions such as, can you tell me what you know about diabetes, how you learnt about diabetes, and what was it like when you first found out you had diabetes were asked during

the interviews. The interview questions addressed the degree of knowledge about diabetes and feelings associated with having a chronic condition. Types of social support provided by family, peers and health care providers were also explored.

Data analysis

The demographic data were recorded onto an excel spreadsheet for descriptive analyses. This provided an overview of the sample composition. A summary of demographic information is organized under Table 1. Each interview was digitally recorded and transcribed verbatim. For basic text analysis, Creswell's (2009) six-step method was applied. During this process, transcripts are prepared and all data are read to obtain a general sense of the information and overall meaning. Coding began and data were organized into chunks or segments of text that were associated with descriptive labels. A list of codes was compiled and revised as subsequent pieces of data were checked and new codes emerged. Codes included concepts derived directly from the interview questions, as well as those that were spontaneously elicited or unexpected, memorable, or indicative of larger theoretical issues. This process provided the basis for generating more specific themes relevant to the paediatric context and as such, elicited additional categories or themes for analysis.

These methods normally generate 4 or 5 major themes (Creswell, 2009) and offer an interpretation or meaning of the data. Specifically, the qualitative analyses included: theme generation illuminating common experiences, meanings and processes of self-care. The data for this study generated six main themes and several sub-themes within the main themes. The main themes included: Self-Care, Knowledge, Feelings, Life with Diabetes, Support from Others and Camp Experiences.

After the data were initially coded and the emerging themes identified, a sample of transcripts were reviewed and the data were re-coded. This provided the opportunity for a nuanced and in-depth understanding of the data. In addition, intra-group analyses within each of the three age groups (5 to 8, 9 to 12 and 13 to 18) were conducted while comparative analyses ensued between the triads of participants. Finally, additional analyses focused on the areas of developmental and cultural issues and their relation to self-care processes. To augment analysis Nvivo, qualitative data analysis software program was employed.

Demonstrating Qualitative Rigour

Trustworthiness in qualitative research offers increased assurance of scrutiny and rigour both in methods utilized in the research as well as the production on findings. Trustworthiness was demonstrated by careful and software- augmented review of interview data. The following established methods were also utilized to heighten trustworthiness.

1. Referential Adequacy by ensuring extensive references verbatim quotes in the text. A thorough review of all quotes was conducted and themes that accurately the themes were included in the finding section.
2. Credibility and consistency in coding data was maintained by the two researchers comparing and matching the coded data for one of the three groups of participants.
3. Peer-debriefing through scheduled meetings with the research team and other healthcare professionals working with children with diabetes in their families.
4. Authenticity was addressed in how participants may benefit from the research. Implications and future directions for research were suggested.

Table 1 Demographic Summary

Total number of Participants: 48 (14 boys and 32 girls)	Young Children	Age 5 to 8 years	16 (5 boys and 11 girls)
	School age Children	Age 9 to 12 years	15 (6 boys and 9 girls)
	Adolescents	Age 13 to 18 years	17 (4 boys and 13 girls)
Cultures and Religions	Diverse	Examples: German, French, Canadian, Indian English, Polish, Islam, Jewish,	
Languages	Several	Examples: English, French, Spanish, Swahili, Somali, Hindi	

Findings

Several key themes were generated from the interview data. These themes include: *Self-Care, Knowledge, Feelings, Life with Diabetes, Support from Others and Camp Experiences.*

The data reviewed here, however, presents a focused analysis involving the key themes of *Self-Care, Knowledge of Diabetes* and the *Feelings* associated with having diabetes. These themes were chosen because they were most prevalent in the data and pertinent to the purpose and research questions of the study. In addition, sub-categories within each theme were created to capture a range of issues and perspectives. Variances in responses within and across groups are presented where possible to illuminate similarities and differences in the findings.

Self-care

As a theme, self-care included all aspects of management that are specifically carried out by children and adolescents on their own to maintain health and wellbeing. The nature and extent of self-care communicated by the participants is reviewed in this section. Furthermore, this section presents the views of children and adolescents on the importance of self-care and documents their discussion on when to initiate self-care. During the interviews, all participants

were asked about their experiences with diabetes and their involvement in self-care. Several aspects of self-care emerged during the course of the interviews. The key sub themes related to the main theme of *Self-Care* are; Importance of Self-Care, Initiating Self-Care and Support from Parents.

Importance of Self-Care

Most participants acknowledged that self-care was both important and necessary. Younger children recognized that some involvement in self-care was necessary and were able to give examples of how they participated in their care. Younger children's involvement ranged from cooperating with parents in identifying highs and lows, carrying out daily routines and occasionally checking their blood sugar level. A seven year old boy said that his job in managing diabetes was "Just to tell them (parents) when I feel high or low" (109). Another seven year old boy said, "I only get a blood sugar. I don't know how to do the needle yet. I'm too young to do it" (112). Those who were able to check their blood sugar expressed satisfaction and used adjective such as "good," "proud," and "happy" when discussing their contributions in managing their diabetes.

School age children, however, were more explicit in expressing their views on why self-care was important. Some children felt they could not rely on others forever and, hence, needed to learn how to self-care early in life, whereas others believed self-care was necessary to cope at school. A ten-year old girl explained, "They need to figure it out on their own. Like you can't go through having diabetes without your mom teaching you. You can't do it with her always doing it for you. Cause when you're 21 you can't do that" (201). Being able to manage their diabetes at school was another reason why children wanted to learn to do things on their own. A ten year old girl explained that she wants to "Prove them (classmates) that I'm not afraid of it" (201)

while another eleven year old girl highlighted the need to be comfortable with self-care before entering high school. According to her, “a diabetic kid in my (her) sister's high school kept his insulin in his locker and then he just does it quick. So I think kids should learn that before they go to high school and start doing their stuff” (207, girl, eleven years).

Autonomy and independence were predominant themes in the adolescent interviews. Several adolescents expressed the need to learn and practice self-care to attain independence. The majority of adolescents (twelve out of seventeen) explained that being able to manage their diabetes gave them the freedom to move around. A 15 year old said, “Honestly, I'd rather be independent with it and stuff” (303, female). Furthermore another adolescent explained, “If you don't know how to do it yourself, you can't go to sleepovers or you can't go to school. Well you can go to school but your mom has to come every time to give you a shot, which is very annoying. And you can't go to parties” (311, female, 15 years).

Initiating Self-Care

While involvement in self-care was seen as necessary, most participant's perspective on when or at what age to initiate self-care differed. The age for initiating self-care proposed by participants ranged from five to fourteen years. One six year old girl thought ten was the right age to start getting involved in self-care “because ten is like a responsible number” (114). Another eleven year old said, “Age eleven, twelve. So that when they hit thirteen and they go to parties and all that, they can have more control over it” (206). A fourteen year old said,

If they are too little, they may not get it so quickly and if they are a teenager, maybe they will understand what to do. I think kids should start to learn around 12, 13, and 14 because they are the teenager age. Because if they are too little, they may not get it so quickly and if they are a teenager, maybe they will understand what to do. (307, female)

In addition, there were two school-age children and three adolescents who felt age was not relevant and it depended on the individual. An eleven year old girl said, “I think it's different for everyone” (204, female, 11 years). Some comments such as “Um, as soon as they feel comfortable doing it” (303 female, 15 years old), “Depending on the kid” (311, female, 15 years) and “I think whenever they feel ready” (316, 16 years) were also shared by the three adolescents.

Support from Parents

Parents play a critical role in helping children and adolescents manage their diabetes. The findings illuminate the indispensable role of parents in supporting children and adolescents with diabetes. All participants recognized the key role of parents in facilitating self-care. They unanimously acknowledged and cherished parental support in managing their diabetes. However, the nature and extent of parental support differed based on age, developmental level, maturity and individual needs.

In general, younger children need both physical and psychosocial support from parents. The majority of younger children (ten out of 17) stated, either mom, or dad, or both parents helped them take care of their diabetes. For example, a six year old girl said, “Mostly my mom cause my dad works so he gets home like at night. And my dad. (He) helps me at night. And on the weekends he helps me” (104). Parents of younger children helped children check their blood sugar, calculate insulin dosage, inject insulin and prepare snacks. A seven year old boy said, “It's daddy who gives me the needles” (109) and a seven year old girl said, “My mom comes and injects me at school” (114).

As evident in the findings of this study, parental support plays a pivotal role in promoting self-care in school age children. With school age children, a gradual shift occurred as parents

began to relinquish their role in favor of children taking more responsibility for self-care. For instance an eleven year old girl explained, when “I was pretty little and my mom did a lot of research on it. Cause she wanted to make sure she knew how to deal with it and as I got older, she told me” (204). Another eleven year old boy said, “They pretty much help me count carbs, and with my needles, and check my log book” (206). At this stage many parents assumed a more supervisory role; they monitored and reminded children of particular tasks. One participant explained,

Well, the little stuff like I forget my insulin a lot cause sometimes you're doing stuff. So you forget to do your insulin at a meal. And then she'd (mother) always remind me and she wouldn't get mad at me when I did forget. She'd just like try and help me come up with ways to not forget. (204)

However, in the adolescent population, even though parental support is highly appreciated the nature and degree of involvement differs according to individual needs. As the findings of this study confirm the needs and wants within the adolescent population vary from requiring or desiring little help to complete dependence. Some adolescents believed they were able to function with minimal assistance with the daily regimen, care, but cherished the psychosocial support. In contrast, others discussed needing both treatment and psychosocial assistance. One fifteen year old male said,

Well my mom, you know, she stayed at home and kind of always been there if I need to phone home and stuff like that. She's always recording my blood sugars and everything like that. She still does most of the recordings (309).

Another 16 year old whose mother generally gave insulin injections said,

I still help measure the insulin and stuff. But I can give myself. It's not something that she'll have to do forever and stuff. I just need more practice. So I can't really put a date on it cause I've only been recently diagnosed (316).

Although most adolescents depended in one way or another on parental support, some acknowledged the necessity for assuming more self-care responsibility and reducing stress on parents. One adolescent admitted that sometimes it is difficult for parents to continue to do everything for them and said, "It is hard because I know that they're dealing with so much being, like parents of three kids and all sorts of stuff that goes on. So, they try their best to help me with it- and, that's fair" (305, female, 17 years).

Taken together, the data relating to the theme of self-care reflect children's and adolescents' beliefs that self-care is important and should be initiated as early as possible. The majority of participants acknowledged that self-care should include the indispensable support from parents. The data show that involvement in self-care depends on the age and maturity of individual children. Although individual differences were evident within each group, there was a definite evolution in self-care, knowledge and feelings across groups.

Knowledge

Knowledge of diabetes represented another major theme in the data. Although, the type and degree of knowledge varied within the groups, findings reflect a gradual progression in knowledge from the younger group to the adolescent group. Within the theme of knowledge, three sub categories; *Types of Knowledge*, *Degree of Knowledge* and *Impact of Knowledge* emerged within the data.

Types of Knowledge

The complexity of diabetes necessitates a deeper understanding and wider knowledge base for children and adolescents to participate in self-care. Children and adolescents in the study shared their understanding of diabetes. They spoke of the disease itself, requirement of management, diet and exercise and complications due to mismanagement of diabetes.

Disease

In the interviews, several children; younger and school-age (more than seventy five percent) exhibited very basic knowledge about diabetes. In general, the younger children knew that a part of their body, called the pancreas, was not functioning well. As a result of the malfunction they were required to take insulin. However, they did not understand the function of the pancreas itself. As one six year old girl explained, “Your pancreas is asleep. It was tired of working” (101). Another child said, “It (insulin) keeps you feeling good” (101, female, 6 years).

School-age children had a slightly better understanding of the pancreas and its functions. One school- age child said, “Cause our pancreas can't make insulin anymore to control the sugars in our body” (207). However, adolescents had more extensive knowledge about diabetes and provided articulate explanations. For example a fifteen year old said, “Well, I know that it's an autoimmune disorder, well, type 1 and it's with your pancreas and your immune system pretty much killed off the B cells, I think it's the B cells in your pancreas”(303, female).

Management

Most participants had age appropriate knowledge about diabetes management. All children mentioned checking blood sugar three to four times a day. A number of participants also knew how to read numbers on the glucometer and what those numbers indicated. Several younger children knew which numbers were very high and very low but few were aware of the

target range for normal blood sugar. Out of the few younger children who knew about the target range, one eight year old girl said, “7.8, 10.8, 9.6, 5.4 are all good numbers and 3.2, 2.8, 1.8 are all bad numbers. My mom tells me that these are all in the target range; these ones are not in the target range” (116). However, most school-age children and adolescents knew the target range. A ten year old boy said,

And then you'll have your glucometer which you will have to test your blood sugar with so that you can make sure that your blood sugar is staying in the safe level which is usually in between 4.5-10. (212)

In addition, school-age children and adolescents also mentioned the need to rotate the spot for the insulin injection. A few school-age children knew it was important to do so but did not know the reason for it. Adolescents, on the other hand explained how the skin gets inflamed and hardened if injections are continually given at the same spot. Interestingly, a few school-age children only, identified different kinds of insulin, and differentiated between the fast acting and the slow acting ones. A nine year old boy said, “H is fast acting. So that's what I use for lunch. Cause you want to get it down fast. If you use N it would work five hours later” (202).

Diet

Most children and adolescents were familiar with their dietary requirements; they knew they had to take something sweet, maybe a juice when their blood sugar was low and inject insulin when it was high. Children and adolescents, in general realized that they were not allowed too much sugar which meant they could not have candies, cakes, pops and ice creams very often. A ten year old girl said, “I'm not allowed to eat a lot of sugar. If I eat too much sugar, my blood sugar goes to high” (201). Some of the older children and adolescents also talked about counting carbohydrates in their food to adjust their insulin dose. An adolescent said,

I do look at the carb listings on most packaging. A chocolate bar is 30 carbs I think so it's like eating 2 slices of bread, which is like a sandwich. I'd rather eat the sandwich than the chocolate bar (308, female, 18 years).

In contrast, there were one or two children who believed that they could eat anything as long as they gave themselves the insulin injection. A nine old boy said, "You can eat anything. But you have to give yourself a needle. Like you're pretty free, you just have to give yourself needles and pokes" (202).

Complications

Almost all children could identify the symptoms of high and low blood sugar levels. For example, an eight year boy said, "So I do know that if I feel shaky I have to tell my mom because I am starting to go low" (115). A seventeen year old said she starts to feel "symptoms such as dizziness, can't concentrate, hunger, I tend to get silly too" (30, female) when she is low.

In terms of knowledge regarding long-term complications associated with diabetes, younger children and school age children had very limited information about complications resulting from diabetes. However, most adolescents understood that prolonged mismanagement resulted in complication such as "your extremities are very important, like diabetes feet and also heart disease and a bunch of crazy long-term effects if you don't handle it well" (304 female, 16 years).

Degree of Knowledge

Although individual differences were detectable in the knowledge of participants within each group, there was a definite advancement on the continuum of knowledge, from the younger group to the adolescent group. The gradual progress in both, quantity and quality, of knowledge was evident in the data. In general, adolescents had most knowledge in all areas while the

younger children not only had little knowledge, but had some incorrect notions about diabetes and its management.

In the younger group, most children were aware of their pancreas not functioning properly and the need for insulin. Identifying highs and lows; another aspect of diabetes knowledge, was evident in younger children. Several younger children understood what fluctuations in blood sugar meant and could identify the symptoms of high and low blood sugar. Another six year old girl (105) while playing with a doll (George) said her friend George could not have banana because his blood sugar was high. When she checked his blood sugar it was at 25. Because his blood sugar was at 25, she explained, he could not eat anything and would have to be injected with insulin.

Not only did the younger children have little knowledge, they also held the most misconceptions. For example, some misconception documented in the interviews were, “diabetes is a medicine” and “my mom says if I eat broccoli that will help. I eat broccoli and everything goes away” (106, girl, six years), “One day when I'm bigger and older (my diabetes will go away)” (113, girl, five years), and the number 88 on the glucometer means, “She's low” (108, girl, five years).

Younger children also had misconceptions about losing a limb or dying. Findings elicited that children had deep rooted inner fears related to high or low blood sugar; they believed that if their sugar became too high or low they would immediately suffer from dire consequences. For example, a five year old said, “If my sugar was high or low I would die” (113). Another eight year old girl said “I can go blind. Lose a leg and have heart problems” (116). When asked if this would happen right away she said, “No. I think a couple days. I'll go blind first, losing a leg second, and I'll have heart problems third” (116).

The data showed evidence of better quality and quantity of knowledge in children and adolescents as they matured. Most school-age children were able to check their blood sugar and inject insulin. As they gained confidence and became more adept at administering injections; they also became aware of the need to change the injection site. A nine year old girl said, “Cause sometimes you don't want to be poking the same spot over and over and over again; the tissue gets like, I don't know” (209). However, adolescents understood the reason for rotating spots and explained, “My legs, my stomach usually. I rotate around. Because when you're giving the needle you're pushing it in, the pressure going down eventually your skin starts to get hard and what happens is it creates a tissue build up, which makes it harder for insulin to be absorbed” (305, female, 17 years).

Adolescents had the most knowledge about diabetes and its management. They were also able to convey their views and perspectives most effectively. Adolescents generally knew more than the other children about diabetes and its management. Adolescents could check blood sugar, inject insulin, count their carbohydrates, manage their diet and calculate their insulin requirement. They were also more cognizant of complications that could occur due to mismanagement of diabetes. Furthermore they understood that prolonged mismanagement resulted in complication and as one adolescent said “your extremities are very important, like diabetes feet and also heart disease and a bunch of crazy long-term effects of you don't handle it well” (304 female, 16 years).

Impact of Diabetes Knowledge

Knowledge of diabetes affects children and adolescents in different ways. Some children felt empowered and in control of their diabetes, whereas others described a sense of fear. As one adolescent said,

Like if you don't (have knowledge) it's kind of like letting diabetes control your life. I don't think that it controls my life. It's a disease I happen to have, which is annoying, but you're not going to move on with your life. You have to take control and do it for yourself so you can be a teenager (311, female, 15 years).

In addition, another adolescent explained how his knowledge empowered him to play sports. He said, "I never really thought diabetics could play sports, until I researched people like Bobby Clarke, um. Yeah. People like that" (313, male, 15 years).

In contrast, one adolescent felt scared and anxious because of her extensive knowledge about diabetes. She said "And I was pretty freaked out especially cause I knew what it was. And in the books, the books are kind of older, and so the treatment methods weren't as good. So I was really freaked out" (317, girl, thirteen years). On the other hand, a nine year old boy said, "So I was really scared whenever I felt low cause I didn't know what to do about it. Well I didn't even know that I felt low" (202).

In summary, the data reflecting the theme of knowledge illuminated some variability in the type and quality of knowledge within and across groups. In general, most participants, regardless of age, appeared to have limited knowledge of diabetes. As many were aware of their limitations, they also expressed a desire for more knowledge. Finally, in the case of younger children, the degree of misconceptions and inaccurate information was particularly salient.

Feelings

Children and adolescents expressed a range of emotions about having diabetes and managing it. Most children, irrespective of age, developmental level, maturity and gender felt strong negative emotions at the time of diagnosis. Beyond the first year of diagnosis, many children and adolescents got accustomed to the strict medical regimen and lifestyle change, but

continued to experience some emotional upheaval. Wishing they did not have diabetes and hoping for a cure, were feelings expressed by a substantial number of participants across the groups. A few (around fifteen) participants, however, displayed some positive emotions. Data analysis within the feelings section elicited three sub-themes: *Diagnosis, Negative Emotions, and Positive Emotions*.

At Diagnosis

Many children and adolescents used words like ‘scared,’ ‘angry,’ ‘sad,’ ‘upset,’ ‘depressed,’ ‘shocked,’ and ‘mad’ to describe their feeling at the time of diagnosis. Children gave a variety of reasons for experiencing these feelings; most were scared of needles while others were concerned about peers ridiculing them or them having to explain their disease to others. For example a ten year old boy said, “I was shocked and scared. Cause I had to take needles and see blood every day” (203). And an eleven year old girl added, “So when they showed me the needles I was like, I’m not going to the hospital. Then I locked myself in the bathroom, it’s like I’m not going. You can’t make me. I’m not taking a needle” (207). Another ten year old girl explained, “That I’d be scared that people would make fun of me” (201). One adolescent also felt sad because, “I was like, oh my God, I’m never going to have sugar again” (317, female, 13 years).

Diagnosis of diabetes and the challenges associated with managing the disease overwhelmed children and adolescents. In addition, early experience with diabetes care also influenced long term adjustment in some children and adolescents. For example a seventeen year old girl said,

So, I was there for like three days of daycare and then I kept coming back and I got familiar with who my dieticians were, nurses and doctors, and I thought like this is my first time at Sick Kids, and I felt pretty special being here so, I got so excited. (301)

In contrast, another seventeen year old girl described her traumatic experience.

And they had a bunch of new nurses who were training, doing like, and helping out at the emergency room. And they had to hold me down on a table and put it in and they did it three or four times. Because they did it wrong. And for like a six year old little kid to sit there and be constantly be jabbed. Like to this day if they put a needle here I cry. I break down crying in the middle of that little clown painted room. Like I'm horrified. (305)

Negative Emotions

Beyond the initial adjustment period, although most children and adolescents became familiar with the diabetes regimen, yet they experienced bouts angry and anxiety. Children and adolescents gave a variety of reason for their negative feelings towards diabetes. One younger child indicated “I don't want diabetes anymore. It's not fun” (104, female, 6 years). Some children found it difficult to manage due to the dietary restrictions. A ten year old girl expressed the need to find a cure for diabetes so that children could “feel free and eat anything they want, but not too much sugar” (201). Another child felt that it could be annoying.

Cause if you get it when you're like around like ten, it's really the worst time to get it.

Cause you're really starting to eat stuff. You've been eating stuff whenever you want it.

And eventually you can't do that. (202, male, nine years)

The high number of injections children and adolescents were required to take every day was another source of stress. A nine year old boy said, “Probably not having to have needles. That would probably be it. I don't really mind having needles, but it's probably the worst thing

about having diabetes” (202). Another eleven year old girl said “The finger poking, I can live with that, but not the needles” (207). An adolescent said, “I wish I could only give myself one shot a day type of thing. Like, I could deal with that - if I didn't have to test as much” (303, female, 15 years).

Children and adolescents who had, in general adjusted well to the diabetes regimen also felt stressed from time to time. They spoke about the difficulties they faced in managing their medical regimen, especially with regard to the dietary limitations in social settings. A six year old girl said,

It's just that sometimes I see something really good that I really want, but I can't eat it. So I feel angry that I can't always eat or drink something that I want to drink. Well it's cause I always want to be with my cousins eating ice cream and running more but I can't have fun with my cousins and friends. (111)

An adolescent built upon the idea and said,

Sometimes like when you're with your friends or when you see people around and they're talking and laughing and they're just eating. Nothing to it. They're just eating. You know? They don't have to think about how much they're eating, what they're eating, what dose of insulin they're going to give, when are they going to give it, are their friends going to notice? Is it going to bother someone? What are the people in the restaurant going to think? Are they going to think I'm a heroin addict if I'm sticking myself with needles in a restaurant, you know? Sometimes if I really need to give myself a shot and I'm in one of those moods where I don't really care, I get looks like, "What's that kid doing?"(303)

Some children and adolescents were also concerned about being isolated from peers. They believed other children would not be their friends with them and would be lonely and miss out on fun. A ten year old girl said “I explained to my friends and some of my friends turned into enemies already” (201). An adolescent said,

Kids can't feel isolated because at one point of their life they are going to because they're different or they're going through something no one else they know of is. I'm the same, I'm no different. You can't just tell kids that they have to concentrate on their diabetes. They have other things in their life like let's have fun. Education is part of it too but having fun with the people who are diabetic too you know? They could have fun as well. They know how to play skipping rope or whatever. (301)

Positive Emotions

Despite the challenges associated with diabetes, some younger children and several adolescents were able to adjust to it. For example a six year girl said, “I’m used to it” (injection) (101). A nine year old boy who knew how to check his blood sugar and inject insulin explained that “Now I don't mind diabetes” (202). Another eleven year old girl said, “You just deal with it, and then you can forget about it and then you can be a normal kid” (207). Furthermore, an adolescent said,

It’s fine. I mean, I have to do it but I really don't mind it. I don't know, I guess it's a bit awkward in public but, I do it in my stomach so I just lift up my shirt and do it. I also use a pen, which is a smaller needle. It kind of looks like a pen too. It's not like I have to draw down the insulin, so it's not quite as sketchy, I guess. (304, female, 16 years)

In addition a few children understood the challenges associated with having and managing diabetes, but yet looked for some positive elements in their situation. Some children

believed life could be worse if they had a more serious problem. A school-age child said, “I wish I didn't have it, but I know I have it a lot better than some people” (204, female, 11 years).

Another eleven year old girl said she is in a better position compared to “a whole bunch of people in Africa and stuff who are my age and they have AIDS” (204). An adolescent took inspiration from her sister who had multiple developmental delays. She said,

So the way I look at it is that if my delayed sister can do it, I can do it. Because I can talk and I can do all those things. I mean she's at a four year old level right now and she's eleven (304, female, seventeen years).

Furthermore some adolescents went even beyond acceptance and described a sense of responsibility for their own health. One fourteen year old said, “I don't know. I feel like it's my responsibility because it's what I have so I don't want to be like a problem everybody else having to deal with me. I'll just deal with it myself” (306, male). Several adolescents believed taking responsibility over one's health represented a higher level of personal acceptance; a key factor in promoting self-care. A seventeen year old indicated “I said to myself, you know what, everybody has to deal with something. And I thought this was going to be a challenge but I have to overcome it” (301, female).

Taken together, the data relating to feelings reflect that ongoing management of diabetes can reliably produce emotional upheaval for children and adolescents of all ages. However, beyond the initial adjustment period most patients with diabetes are able to cope with the day to day management of diabetes. The data also illuminated that some adolescents were able to cope better with the challenges associated with diabetes because they accepted their situation and took responsibility for their health.

Discussion

Children and adolescents with diabetes live with a complex condition that necessitates substantial lifestyle changes. Despite the complexity, children and adolescents in this study were able to share their self-care experiences, knowledge of diabetes and feelings associated with having the disease. As acknowledged by the participants, the challenges associated with the management of diabetes in the paediatric population are salient and profound; yet many are able to overcome obstacles and engage in self-care. This section discusses the integrated themes of self-care, knowledge and feelings and how these findings can inform clinical practice.

This study replicates the findings of earlier studies addressing self-care in children and adolescents with diabetes. For example, previous research has cited age and development as strong contextual variables (Hanna & Decker, 2010; Palmer et al., 2007; Schilling et al. 2002). Evidence of the importance of age and development in managing diabetes is documented throughout these findings; adolescents are more involved in self-care, have more knowledge and reflect more emotional maturity in comparison to the younger children. Despite the evolution of self-care over time, children and adolescents require continued support from others. Even though, self-care, knowledge and feelings definitely evolve with age and maturity, the need for ongoing treatment and psychosocial support continues much into adulthood.

The data also revealed that types and degree of knowledge varied within and across the participant groups, reflecting the complexities and nuances in children's understanding of the disease. These findings also allude to the need for more consistency in how we educate children and adolescents about diabetes. A disconcerting finding in this study involves the limited knowledge exhibited by the younger children and some school age children. More specifically, younger children had little knowledge of their disease and they held several misconceptions.

Some younger children believed they would get cured if they ate broccoli, or they would grow out of it while others thought that if their sugar went high or low, they could lose a limb or die within a few days. Such misconceptions can create anxiety and inhibit the development of self-care. Therefore, these findings draw attention to the educational needs of younger children if self-care initiatives are to start early as suggested by several of the participants in this study and previous researchers (Chaney et al., 2010; Roper et al., 2009; Swift, 2007). For greater self-care to evolve, children and adolescents must be receptive towards gaining knowledge and learning about diabetes (Lange et al. 2007).

In terms of feelings, the data confirmed earlier findings related to trauma at diagnosis and adjustment to the daily regimen over time (Cammarata et al., 2009; Silverstein et al., 2005). As shown in this study, children and adolescents with diabetes experience a range of emotions at the time of diagnosis. Children and adolescents, who had no prior knowledge of diabetes, were suddenly burdened with the daunting tasks of checking blood sugar levels, injecting insulin and managing their diets. The lack of knowledge (Howells, 2002; Narumi, 2012; Roper et al., 2009; Swift, 2007) and the invasive regimen (Silverstein et al., 2005) together, can cause anxiety in children and adolescents. The fear of needles in the younger children has also been documented in literature (Howe et al., 2011; Rzeszut, 2011) and substantiated in this study.

Beyond the initial adjustment period, most children and adolescents were able to cope with the daily regimen of diabetes as evident in the finding of this study. Despite coping well with the diabetes regimen, several participants expressed negative emotions. Literature reveals children and more so adolescents find it difficult to navigate through the emotional and psychosocial challenges of having diabetes (Cammarata et al., 2009; Faulkner, 2003; Silverstein et al., 2005). School-age children and adolescents in particular, found having diabetes

emotionally taxing because it made them dependent on others. Children and adolescents felt that they could not go to places and environments where others had no knowledge and experience with diabetes. As explained by one adolescent in the study, “When I go to my aunt, my mom's biggest sister, she used to be a nurse, helps me. Sometimes I spend the night at my mom's other youngest sister. She knows what do to as well” (310). As noted in this study, and acknowledged in the literature, diabetes can affect the psychosocial well-being of children and adolescents because it impedes their evolving independence and autonomy (Cammarta et al., 2009; Ivey et al., 2009; Karlsson et al., 2006 & Leonard et al., 2005).

These findings also confirm previous research that highlights the significance of parental support (Nurmi & Stieber-Roger 2012; Sherifali, Ciliska & O’Maraa, 2009; Silverstein et al., 2005; Sullivan-Bolyai, Rosenberg & Bayard, 2006). More specifically, parents of younger children carry more emotional burden as well as the stress of day to day management of their children’s diabetes (Lowe, 2008) compared to parents of school age children and adolescents (Lowe, 2008; Marshall et al., 2009). As children transition from middle childhood to early adolescence, they become more adept at self-care and want greater autonomy in terms of carrying out the daily (Karlsson et al. 2006). Although adolescents identified the need and want for greater autonomy in the day to day management of their diabetes, most desired continued emotional support from parents. All participants acknowledged that parental support is an indispensable factor in their ability to cope with diabetes. However it was noted that despite parental support and ongoing attempts to manage the disease, many children and adolescents are unable to accept their diagnosis of diabetes. The findings reflect that parental support can reap maximum benefit when it is aimed towards promoting autonomy as opposed to making children more dependent on them.

Despite the adoption of a theoretical framework which viewed children as competent and capable research collaborators, it is difficult to ignore the developmental issues that permeate the literature in this area. Indeed, even the participants in this study were grouped into three age categories in order that developmental issues could be addressed. Although all of the participants provided valuable insights regarding factors that may elicit, sustain or inhibit self-care, age and developmental differences were evident in the data. These differences necessitated additional comparative analyses between the three groups of participants. In turn, these analyses provided accessible recommendations or practice guidelines for health care professionals. Despite these developmental considerations, the notion of acknowledging children's rights remains paramount regardless of the child's age and abilities.

The Integrated Themes of Self-Care, Knowledge and Feelings

In this study, the main research questions addressed the involvement of children and adolescents with diabetes in self-care as described by the participants themselves. This paper presented a focused analysis of the data regarding children's and adolescents' knowledge of diabetes, their feelings, and involvement in self-care. In turn, an interpretation of the data reflects knowledge, feelings and self-care as inter-related constructs; each contributing to the overall adjustment and management of diabetes. By reviewing the integrated themes, it is reasonable to assume that the emotional challenges faced by children and adolescents hinder the process of knowledge acquisition and self-care. The findings of this study expose the need for greater attention regarding acceptance and personal responsibility in promoting self-care.

According to Zalewska, Miniszewska, Chodkiewicz & Narbutt (2006), acceptance can be defined as a realization and recognition by patients, of the reality of having a chronic condition. "Patients should be ready and willing to cope with restrictions and changes in everyday life

imposed by the chronic condition” (Zalewska, et al., 2006, p. 236). Acceptance, however, can be a major problem for many patients who coping with chronic illnesses (Court, Cameron, Berg-Kell & Swift, 2008; Sanders, Odell & Hood, 2010; Howells, 2006; Zalewska, et al., 2006). A lack of or a low level of acceptance can have a negative effect on patients and can lead to non-adherence to medical treatment and poor management of the illness (Court, et al., 2008; Hood, Odell & Sanders, 2010; Howells, 2002; Zalewska, et al., 2006). Accordingly, “acceptance” is critical for engagement in self-care.

The adolescents in this study who expressed acceptance of their medical condition also showed evidence of greater knowledge and involvement in self-care. For example, an adolescent who had substantial knowledge and involvement in self-care said, “Well you know, I guess the most important thing is the responsibility part. You say, I'll take control of it (diabetes)! It's just there. Something in your life that's there and you just gotta take control of it so” (309).

In contrast, the majority of participants in this study who did not reflect a certain level of acceptance appeared to have only basic knowledge about the disease and limited involvement in self-care. As stated by an adolescent it is easier

not to acknowledge it (diabetes) than to acknowledge everything. Like for me everything just coming towards me like if I acknowledge everything than it would be a lot more trouble than not acknowledging it at all. (308)

Although it is not possible to cite causation, it appears reasonable to assume that the degree of knowledge and level of emotional adjustment play important roles in the evolution of self-care. As noted by one adolescent,

Well, I got tired of my parents always having to do it for me. So, my mom showed me a couple of times and from watching her so much earlier, I learned. I just wanted to be

more independent. I think it made me feel a bit better about it too, having that responsibility to do it myself and to show my parents that I could do it. It definitely made me grow up a lot faster. (305)

Another adolescent expressed a similar sentiment by acknowledging the links between obtaining a sense of responsibility and having the ‘right kind’ of parental support.

They just probably reassured me that I can still live a normal life and everything and honestly just keep control of it and everything will be fine and, you know, I kind of learned from them that as long as you keep a good positive perspective on diabetes you can just take better control over it and learn how to get used to it and give yourself treatments and stuff like that and it just makes life a lot easier like that so they've always kind of influenced me to take initiative and do some of my stuff. So once I got used to it, it was really good” (309).

An important aspect of adaptation begins with the acknowledgement that as key stakeholders, children and adolescents with diabetes have the right to participate in the discourse associated with self-care. Giving children and adolescents a voice should consist of more than just listening to what they have to say, but ensuring a foundation for a tenable support structure over the long term (Dockett, Einarsdottir, & Perry, 2009). For children and adolescents to be supported in the management of their disease, physicians, researchers, parents, peers, and educators must pay heed to their views, opinions and perspectives. Educational and psychosocial programmes, therefore, must be tailored towards the specific needs identified by this population (Chaney, et al. 2011). It is within this conceptual framework that we can design an approach that maintains emotional and treatment support through adolescence with particular emphasis on

building knowledge and self-care at an early age. In turn, degrees of personal acceptance and responsibility will elicit gradual self-care leading to positive long-term health outcomes.

In summary, it can be inferred that listening to children's concerns, offering emotional support and developmentally-appropriate information about their disease can lead to greater acceptance and self-care over the long term. By addressing the emotional challenges and learning about the disease and its treatment, there is a greater likelihood that acceptance can lead to engagement in self-care. If children are not emotionally supported by others around them, they may reject diabetes education making acceptance of the disease difficult to achieve. In other words, if children's knowledge of diabetes is minimal, there is little hope they will engage in self-care.

Implications for Practice

To promote knowledge and self-care in children and adolescents with diabetes, it may be important to examine the support structure scaffolding the emotional and psychosocial development. The three main environments supporting paediatric diabetes management are: the medical environment, the home environment and the school environment. The participants in this study rarely mentioned the support they received from the medical team; most children spoke of learning from their parents and receiving emotional support from them. However, research cites the critical role of health care professionals in supporting children and adolescents with diabetes (ADA, 2012; CDA, 2012; JDRF, 2012; Silverstein et al., 2005).

With regard to external supports, the lack of support often received in school exacerbated the emotional upheaval associated with diabetes. For example, participants in the study shared their apprehension about managing their diabetes at school. Having diabetes and being in school appears to be challenging for three reasons. For one, children and adolescents believed that

teachers and staff did not know enough about diabetes. In turn, they were concerned about what might happen in the case of an emergency. Accordingly, research highlights the need for children to be capable of self-care because nurses and school staff may lack knowledge about diabetes and may not be comfortable handling diabetes related emergencies at school (Nabor et al., 2003; Nabors, Troillett, Nash & Masiulis, 2005). Due to a lack of knowledge of diabetes among school nurses, a growing number of children using the insulin pump are afraid of problems and malfunctions with the apparatus at school. Darby (2006), in her study on the experiences of school nurses caring for children using the insulin pump, found that nurses were initially scared, but gained more confidence with knowledge and hands on experience.

Second, many children find it difficult to incorporate diabetes care into the school routine because of the fear of losing friends. Children and adolescents diagnosed with diabetes are apprehensive about how the diagnosis would impact their friendships at school and other peer relationships. These concerns are aligned with findings from other research where peers were often rejecting of their chronically-ill counterparts (Pallidino et al., 2012). The findings of this study confirm that children and adolescents fear losing friends who are important to them. Peer support has been identified as a factor that can either hinder or facilitate adjustment to diabetes in children and adolescents (McCarroll, Lindsey, MacKinnon-Lewis, Chambers & Frabutt, 2009; Palladino et al., 2012). Research also suggests that chronic illness can contribute to lower levels of social competence and hence difficulty in maintaining social relationships (McCarroll et al., 2009). In view of the findings of this study and earlier research (McCarroll et al., 2009; Palladino et al., 2012), it is imperative to promote social competence in children with chronic illness.

Finally, children may feel embarrassed if, in any way, they seem different from their peers at school. Findings reflect children's concerns about being singled out because of their medical needs. Hence, they avoided discussions in fear of being set apart from their peers. In particular, the younger participants found it difficult to explain diabetes to peers and answer questions. Research confirms that children with diabetes are sometimes self-conscious because they may be different in some ways (Kelo, Martekainen & Eriksson, 2011).

Taken together, these findings and those of others (ADA, 2012, Cammarata, et al., 2009; Gaston et al., 2011; Kelo et al, 2011; McCarroll, 2009; Palladino et al., 2012) reinforce the need for greater support from the medical team, parents and school personnel. As integrated themes, self-care can be enhanced when the psychosocial needs of the child or adolescent with diabetes are met. They are more likely, in this context, to reach a level of acceptance which can make them more open to learning about their disease.

This process is reiterated by others who note that the diagnosis of diabetes has an effect on self-efficacy and self-esteem in young persons (Court, et al., 2008; Sander, Odell & Hood, 2010; Howells, 2002). Self- efficacy is a person's belief in his or her ability to overcome difficulties inherent in a particular task (Howells, 2002). Accordingly, children and adolescents who believe in themselves and accept the positive and negative aspects of life usually achieve a healthy self-esteem while mastering health-related behaviours. The finding of this study also coincide with research that children who accept their diagnosis have more knowledge and better self-care (Court, et al., 2010; Howells, 2002; Sander, Odell & Hood, 2010).

As these findings attest, education and knowledge dissemination are extremely important for supporting children and adolescents with diabetes (ISPAD, 2007, Swift, 2007; Swift, 2000). Research substantiates the need for programmes that combine diabetes education and

psychosocial interventions. Murphy, Rayman and Skinner (2006) conducted a comprehensive literature review of 27 articles describing 24 psycho-educational interventions. The research aimed to find sufficient evidence of effectiveness of intervention to recommend further for adaptation and implementation. The result reflected that the quantity and quality of educational research had not resulted in improved effectiveness of interventions. The findings of this study in conjunction with other findings (CDA, 2005; Murphy et al., 2006; Swift, 2007) reflect the need for research that explores children and perspectives and creates intervention based on needs identified by the patients themselves.

Children and adolescents with diabetes and their families have differing needs based on their unique situation. In recognition of the diversity in family composition, culture, religion, ethnicity and socio-economic status, researchers are constantly evaluating and formulating intervention techniques to meet the changing needs of this population. For instance, the Canadian Diabetes Association (CDA) (2005) in recognition of the need to provide diabetes education to children and adolescents identified best practices from around the world. For children and adolescents with Type 1 diabetes, the CDA identified two best practices; Educational Video Game-Packy and Marlon, and Diabetes Personal Trainer. Packy and Marlon is a video game for children between the ages of eight and sixteen. This video game is designed to promote self-confidence, ability and motivation in children. Diabetes Personal Trainer is an intervention for adolescents between the age of eleven and sixteen and is designed to motivate adolescents to better self-care. The personal trainer takes a strength based approach and emphasizes developing individual strengths. The personal trainer facilitates adolescents to introspect, look for strength within, and based on those strength manage the prescribed medical regimen and take responsibility for self-care.

Considering that the age for diagnosis has decreased over time and is becoming lower with passing time (IDF, 2012; JDRF, 2012), it may be important for practitioners to re-assess and re-evaluate when and what information they provide to young children and their families. In particular, these issues appear important in the case of younger children who would benefit from ongoing child life involvement where education can be offered using developmentally-appropriate interventions. These issues are not only relevant for younger children, but for older children and adolescents too. As recognized by the majority of participants, they had limited knowledge and desired additional knowledge about their illness. With more knowledge and better communications, it is believed that children and adolescents with diabetes could reach a level of acceptance leading to self-care.

Accordingly, physicians, nurses and diabetes educators should incorporate proven educational methods in their practice. For example, the American Paediatric Association (APA) (2008) highlights the importance of effective communication between the patients, their families and the medical practitioners. The reports states,

Communication is the foundation of the therapeutic relationship; it is the basis of fiduciary and ethical obligations of physicians to patients and their families. Effective health care communication is an essential tool for accurate diagnosis and for the development of a successful treatment plan, correlating with improved patient knowledge, functional status, and adherence to the agreed-on treatment regimen, improved psychological and behavioral outcomes, and even reduced surgical morbidity. In the case of distressing news, skillful communication can enable a family to adapt better to a challenging situation, including a child's unanticipated impairment. Poor

communication, on the other hand, can prompt lifelong anger and regret; can result in compromised outcomes for the patient and family (APA, 2008, p.1441).

In addition, the report mentions the need for “curricular emphasis on building interpersonal skills in pediatric service or training” (APA, 2008, p.1442). Shield, Tong, Tomas & Besdine, (2011) contend, though communication skill education is gaining significance in medical schools, several barriers hinder its implementation and maintenance. “Medical students are socialized early into the traditional authoritarian physician role in their training by the subtle and not so subtle messages of the ‘hidden curriculum’ that implicitly teach students that their place is at the top of the medical hierarchy” (Shield et al., 2011, p.408). According to Shield et al. (2011) as medical students gain more medical knowledge and related skills, they “may often perceive that establishing rapport and maintaining empathetic listening are less important in the physician-patient encounter” (p.408). Other researchers have substantiated these claims and found that medical curricula in general have not given due importance to courses on building communication skills (Bombeke et al., 2010; Pederson 2010).

Strengths and Limitations

Taken together, this study contributes to our understanding of the processes involved in promoting and sustaining self-care for young persons with diabetes. Perhaps most importantly, children and adolescents with diabetes acknowledge the value of self-care and the significance of promoting a strong knowledge base and emotional support at an early age. This study illuminated the importance of acceptance and its influence on knowledge acquisition and self-care. Although it is not possible to establish a causal relationship between acceptance and knowledge and self-care, these links can be inferred based on this study and those of previous

studies concerning children with chronic conditions (Court, et al., 2008; Howells, 2002; Sander, Odell & Hood, 2010).

Limitations of this study include issues of generalizability and the extent to which these findings can be applied to other settings or contexts. Although participants were recruited from an outpatient clinic, which served children and adolescents from a wide range of cultural backgrounds, the findings cannot be generalized and applied to children and adolescents from all cultures and ethnicities.

Future Research

The findings of this study emphasize the role of emotional and educational support in ameliorating poor diabetes control. Future research should explore the notion of acceptance and its influence on self-care especially in children and adolescents with diabetes. For example, what approaches can be used by health care providers, educators and parents to promote a level of acceptance? How can acceptance be fostered at an early age or soon after diagnosis? Are there certain children or adolescents who may never reach a level of acceptance based on their life circumstance or individual temperament? Interventions promoting greater self-efficacy may promote acceptance of diabetes in children and adolescents. As noted by Zalewska et al. (2006) “enhancing levels of optimism and self-esteem and minimizing one’s convictions that one’s health depends on others would lead to higher acceptance of illness” (p. 241).

Appendix A

Definition of Key Terms	
Management of Diabetes	Making lifestyle adjustments as well as adhering to a strict regimen. It includes self-care and support from parents and caregivers.
Self-Care	Those aspects of management that are specifically carried out on his/her own, by the child or adolescent to maintain health and well-being.
Diabetes	A disease in which the body's ability to turn food into energy is impaired. The process of turning food into energy is called metabolism. In order to metabolize sugar, the body requires a hormone called insulin. When the body does not metabolize sugar it is usually due to either lack of insulin or insulin not working properly (JDRF, 2012). Type 1 diabetes is caused by a lack of production of insulin (Canadian Diabetes Association, 2012). In this paper the word diabetes only denotes Type 1 diabetes.
Paediatric Population	Children and adolescents between the ages of 5 and 18 years.

Appendix B

(Child Interview Sample Schedule)

1. Can you tell me what you know about diabetes?
2. What was it like when you first found out you had diabetes?
3. How did you learn about diabetes?
4. Do you think you know enough about diabetes or would you like to know more?
5. When people around you are talking about diabetes, are you a part of what is being talked about?
6. Who helps you take care of your diabetes?
7. What kinds of things do they do?
8. How much do you help when it comes to taking care of your diabetes?
9. Tell me about the things that you do to take care of your diabetes?
10. What was one of the first things you did by yourself? How did you feel after you did it?
How did you feel about helping out? (Introduce feelings faces)
11. What is the best thing about taking care of your diabetes?
12. What things are you doing now that you weren't doing before?
13. How important is it for you to be helping out with your diabetes?
14. What do you think would happen if you didn't help out with your diabetes?
15. When do you think kids should start helping with their diabetes?

Appendix C

(School-age and Adolescent Interview Sample Schedule)

1. Can you tell me what you know about diabetes?
2. What was it like when you first found out you had diabetes?
3. How did you learn about diabetes?
4. Do you think you know enough about diabetes or would you like to know more?
5. Who helps you take care of your diabetes?
6. How much do you help when it comes to taking care of your diabetes?
7. Tell me about the things that you do now to take care of your diabetes?
8. When you think about your role in managing your diabetes, how important is it for you to be involved in your care and why?
9. What do you think would happen if you decided not to do anything about your diabetes?
10. What do you hate most about having diabetes? Is there anything positive about having diabetes?
11. Are there some people who have been really helpful in managing your diabetes?
12. Can you tell me about your friends? What are they like?
13. When adults are talking about your diabetes, are you a part of the discussion?
14. What kinds of things can adults do to make it easier for teens with diabetes?
15. What kinds of things help kids and teenagers get involved in caring for their diabetes?
16. What kinds of things make it hard for kids and teenagers to get involved in caring for themselves?
17. If you could change one thing about having diabetes, what would it be?

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