

THE LIVED EXPERIENCE OF SOCIAL SUPPORT  
IN ADOLESCENT DIABETES PATIENTS

by

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## ABSTRACT

Adolescence is a time of change in many aspects of a person's life, and this time is further complicated by the presence of a chronic illness such as diabetes. Further, the metabolic control exhibited by teens is generally worse than at other points in life, with as many as 30-50% being characterized as out of control. Despite extensive research on the interaction between the social milieu and diabetes control, results have been inconclusive or contradictory. The purpose of this study was to explore how adolescents ages 12-18 experience social support from friends and peers. A convenience sample of adolescent patients from three clinics in a small city in south central Montana were interviewed regarding friendships, use of insulin delivery devices, social networking, and the impact of diabetes on social interaction and daily life. An inductive analysis approach revealed nine themes: full disclosure, taking care of myself, getting help, making it a part of life, people who know are important, sharing information as positive, adults as negative reactors, age differences make a difference and heavy issues early in life. Technology, such as insulin pumps and online social networking, was found to have a major positive impact in participants' social functioning and control. Peer relationships with other teens with diabetes were found to be important and different from friendships with non-diabetics. Negative reactions and social impacts were found to be much more prominent from adults than from same age peers. Implications include the need for further investigation of how technology might benefit teens with chronic conditions, the potential for positive impact from peer connection and mentoring programs, and the importance of clinicians' awareness of patients' social functioning as it impacts care behaviors and general well being.

## CHAPTER ONE: INTRODUCTION

Adolescence is a unique developmental period during which many aspects of a person's life undergo major changes, including one's capability to manage one's own health behaviors and social interactions (Cheung, Cureton, & Canham, 2006; Karlsson, 2008). The transition from childhood to adulthood is complex for the average adolescent, but the presence of a chronic diagnosis adds complications (Karlsson, 2008). Normal adolescent development includes a shifting of the primary source of social support from a teenager's family to his or her friends, but conflict between normal development and the care needs of a patient with a chronic illness can interfere with both development and care (Carroll, 2006; Cheung, et al., 2006; Colarossi, 2001; Helgeson, Lopez, & Kamarck, 2009). This research is aimed at understanding how adolescents with diabetes experience social support received from friends and peers.

Purpose

It is well established that self-management of diabetes is necessary for improving the health outcomes of diabetics (Edwall, Hellström, Öhrn, & Danielson, 2008; Sousa, Hartman, Miller, & Carroll, 2009; United States Department of Health and Human Services Centers for Disease Control and Prevention, 2008). Further, studies show these management behaviors are impacted by a person's choice whether or not to disclose a chronic health condition (e.g. diabetes) (Berlin, Sass, Davies, & Hains, 2002). In order for healthcare professionals working with these patients to assist them in improving their health, interventions must be built on a realistic picture of the patient's daily life. It is,

therefore, the purpose of this research to explore the experience of friend and peer support by adolescents with diabetes and, by so doing, to expand understanding of the variables underlying adolescent behavior to work toward crafting more effective intervention strategies for their long-term health promotion.

### Background and Significance

#### Chronic Illness

Chronic illnesses often require ongoing treatment and self-management behaviors by the patient, which may be in conflict with the desires of the patient, as well as potentially interfering with social relationships (Cudney, Sullivan, Winters, Paul, & Oriet, 2005). Training and support for self-management have been shown to both improve outcomes for adult patients and reduce healthcare costs, but some researchers argue that the focus of many studies has been too narrow on medical outcomes and has failed to account for the patient's broader psychosocial outlook (Dovey-Pearce, Doherty, & May, 2007; Harvey et al., 2008). This study has focused on adolescents with diabetes, largely because diabetes is "a labor-intensive chronic illness that is qualitatively different from many other chronic illnesses; there is never a time when one can hope for remission or a hiatus from the work of disease management" (Ayala & Murphy, 2011, p. 50). Thus, diabetes provides a relatively steady state in which to examine the lived experiences of adolescents who have a chronic illness.

## Diabetes

Data from the U.S. Dept. of Health and Human Services Centers for Disease Control and Prevention (CDC) underlines the severity of the diabetes problem among young people in the United States. Regarding the prevalence of type 1 and type 2 diabetes mellitus:

- “Diabetes is one of the most common chronic diseases in children and adolescents; about 151,000 people below the age of 20 years have diabetes” (United States Department of Health and Human Services Centers for Disease Control and Prevention, 2010, More information section, para 1).
- 13,000 young people are newly diagnosed with type 1 diabetes each year (United States Department of Health and Human Services Centers for Disease Control and Prevention, 2010).
- 3,700 new cases of type 2 diabetes are diagnosed in US residents under 20 each year (United States Department of Health and Human Services Centers for Disease Control and Prevention, 2008).

Complications arising from diabetes during the patient’s lifetime can include heart disease, stroke, hypertension, blindness, kidney disease, nerve damage, amputations, dental disease, pregnancy complications, impaired healing and recovery from illness, and potentially life-threatening metabolic imbalances such as diabetic ketoacidosis and hyperosmolar nonketotic coma (United States Department of Health and Human Services Centers for Disease Control and Prevention, 2008). Further, the CDC identified diabetes as the seventh leading cause of death listed on death certificates in 2006 (United States

Department of Health and Human Services Centers for Disease Control and Prevention, 2008). The same report by the CDC emphasized the possibility that death related to diabetes is highly underreported – only 35-40% of deceased persons with diabetes have it listed on the death certificate at all (2008).

Beyond the cost the individual faces in terms of health deficits, the financial impact on a national level from diabetes is staggering. In 2007, the CDC estimated \$174 billion in total costs: \$116 billion in direct medical costs and \$58 billion in lost revenue due to disability and premature death (2008).

### Glycemic Control

The negative outcomes of diabetes are not guaranteed. Patients who improve their glycemic control have been demonstrated to significantly improve their outcomes:

Studies in the United States and abroad have found that improved glycemic control benefits people with either type 1 or type 2 diabetes. In general, every percentage point drop in A1c blood test results (e.g., from 8.0% to 7.0%) can reduce the risk of microvascular complications (eye, kidney, and nerve diseases) by 40% (United States Department of Health and Human Services Centers for Disease Control and Prevention, 2008, Preventing diabetes complications: Glucose control section, para. 1).

Adherence to self-care regimens has been demonstrated to be one key predictor of improved glycemic controls, and thus of improved long-term health outcomes (Brownson & Heisler, 2009; Casey, Eime, Payne, & Harvey, 2009; Heisler, 2009; Vandam et al., 2005). Clearly, understanding how to assist patients in adherence is necessary to reduce both the negative impacts of this condition for individual patients and the general economic costs. This has special relevance for patients in the adolescent population because adolescence is a critical period for developing health promoting behaviors and

attitudes among both healthy and chronically ill teenagers (Guthrie, Loveland-Cherry, Frey, & Dielman, 1994; Hendricks, Murdaugh, & Pender, 2006; Hendricks, Murdaugh, Tavakoli, & Hendricks, 2000; Wu & Pender, 2005).

### Social Support Among Adolescents

While parents represent the greatest source of social support for preadolescents, during adolescence the focus shifts to peers. Middle adolescents, older adolescents and young adults tend to look more outside familial relationships for support and modeling of lifestyle choices (Burroughs, Harris, Pontious, & Santiago, 1997; Pender, Murdaugh, & Parsons, 2011; Thomas, Peterson, & Goldstein, 1997). “During this time, peer support may be a more important determinant of QOL [quality of life] than parents, health professionals, and teachers may think” (Cheung, et al., 2006, p. 57).

### Problem

Previous research on social support in chronic illness has focused largely on either adults, or, when addressing adolescents, on *parental* social support (Burroughs, et al., 1997; Cheung, et al., 2006; Karlsson, 2008; Malik & Koot, 2009; Viklund & Wikblad, 2009). Research has also been lacking in how this age group uses technology – e.g. social networking websites – to augment their social support.

### Research Question

This research will work toward improved prediction and intervention for adolescent diabetes management by addressing the question of how these patients experience social support provided by friends and peers.

### Conceptual Framework

Pender's Health Promotion Model (HPM) will serve as the theoretical framework for this research (Pender, et al., 2011; Sakraida, 2010). The HPM is designed to provide holistic insight into how persons interact with their environments, both interpersonal and physical, as they pursue health (Pender, et al., 2011, p. 44). A graphic representation of this model is available as Figure 1.

The HPM differs from some other behavioral models, such as the Health Belief Model, in that it does not focus on avoiding illness, but rather on a person's desire to realize their health potential (Pender, et al., 2011; Sakraida, 2010). This lack of avoidance makes this model particularly applicable to this research, because "avoidance oriented models of health behavior are of limited usefulness in motivating overall healthy lifestyles, particularly in children, youths, and young adults, who often perceive themselves to be invulnerable to illness" (Pender, et al., 2011, p. 44).

Interpersonal influences (including social support) are considered a determinant in an individual's ability to commit to a plan of action within the HPM (Pender, et al., 2011). Key to understanding this determinant in this model is the understanding that it is the individual's perception, rather than any empirical reality, that sways behavior, and

that this perception operates within a feedback mechanism. In other words, how a patient feels about their ability to accomplish a goal affects how effectively they attempt it, and their perception of progress will reinforce or undermine their continued attempts, as will their perception of the support they receive from the people around them (Pender, et al., 2011).

Once again, the HPM is particularly applicable to research among adolescents because it takes into account the importance of social feedback, as well as how it can vary according to developmental stage. Pender, Murdaugh, and Parsons go so far as to write, “Susceptibility to the influence of others may vary developmentally and be particularly evident in adolescence” (Pender, et al., 2011, p. 48).

### Assumptions

A primary assumption underlying this research is that understanding how adolescents modify their behavior will allow more effective interventions to be crafted. Along with this goes the assumption that interventions by nursing professionals can be effective in assisting adolescents modify their behavior in health promoting ways.

### Definitions

Diabetes: “Diabetes is a group of diseases marked by high levels of blood glucose resulting from defects in insulin production, insulin action, or both” (United States Department of Health and Human Services Centers for Disease Control and Prevention, 2008). For the purposes of this research, the term “diabetes” will include both

Type 1 diabetes, formerly referred to as insulin-dependent diabetes mellitus (IDDM) or juvenile-onset diabetes, and Type 2 diabetes, previously referred to as non-insulin-dependent diabetes mellitus (NIDDM) or adult-onset diabetes (United States Department of Health and Human Services Centers for Disease Control and Prevention, 2008). It will not include gestational diabetes, which is a form of glucose intolerance unique to pregnancy (United States Department of Health and Human Services Centers for Disease Control and Prevention, 2008).

**Social Support:** “Social support refers to the social interactions within the network that are sensed as being available and supportive (perceived) or that actually provide support (received)” (Pender, et al., 2011, p. 218). This definition is broad, and both friend support and peer support have been noted to fall under the umbrella of social support. It is also worth noting that the term “social support” most often implies positive support – other terms, such as “social pressure,” are usually used to distinguish social interaction that has a negative impact on care (Vandam, et al., 2005). This is not, however, universally observed, and exceptions in the literature will be specified.

**Friend Support:** Friend support will refer to any support received or perceived by the adolescent from any person outside that patient’s family whom that patient considers a “friend.” Exceptions are persons who fall under the definition of peer support or professionals with roles in caring for the adolescent that fall outside social interaction (e.g. healthcare professionals, teachers).

**Peer Support:** The term *peer support* will be distinct from *friend* or *social support* for the purposes of this research. Peers will be defined as persons sharing the same

diagnosis; in this case, references to *peers* will indicate persons who share the adolescent’s diagnosis of diabetes. As written in one 2009 study, “...peer support is essentially a relationship created specifically to enable sharing of experience and knowledge with others who are facing a similar health-related issue and to provide social and emotional support.” (Hughes, Wood, & Smith, 2009, p. 397). When referring to persons belonging to the adolescent’s age group who do not necessarily share the adolescent’s diagnosis, the term *same age peers* will be applied.

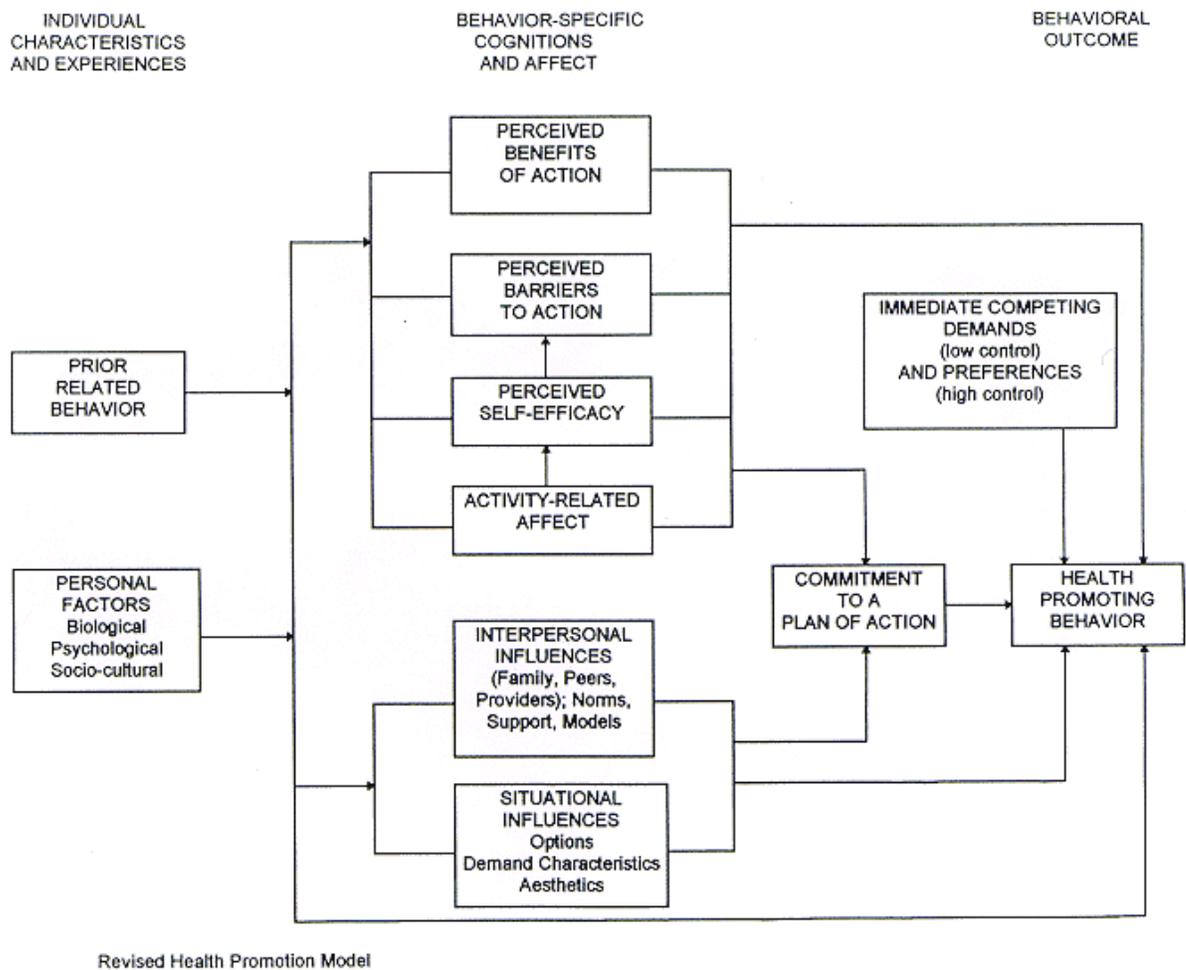


Figure 1: Pender’s Health Promotion Model  
 Graphic courtesy of <http://hdl.handle.net/2027.42/85351>. Used by permission.

## CHAPTER TWO: REVIEW OF LITERATURE

A review of the literature pertaining to adolescent diabetes patients, their social supports, and Pender's Health Promotion Model revealed a wealth of study in this area, but also demonstrated that there are unanswered questions to be further addressed. A search of the CINAHL, PubMed and PsychInfo databases during 2010 and 2011 using the terms adolescent, teen, diabetes, lived experience, phenomenology, peer support, friend support, social support, rural, and Pender yielded 159 unique, relevant sources. Only peer-reviewed, published sources in English were included. Sources were considered without regard to year of publication in order to more clearly understand how understanding of these issues have evolved over the last three decades (earliest article deemed relevant was published in 1979).

Some studies were included regarding chronic conditions other than diabetes, most frequently asthma. This is based on data that indicates young people with chronic illnesses have similar difficulties that are not disease specific and can be studied in combination (Herzer, Umfress, Aljadeff, Ghai, & Zakowski, 2009). Studies investigating cancer were excluded because adolescents have been shown to view it differently from other illnesses (Rechner, 1990). Also excluded were studies of conditions with obvious physical differences, because one of the areas of interest is the choice to disclose diabetes to same age peers or not, and many adolescents with physical disabilities do not have such a choice.

### The Challenge of Diabetes in Adolescence

The difficult and ongoing nature of self management in diabetes is well established (Ayala & Murphy, 2011; Casey, et al., 2009; Dashiff, Vance, Abdullatif, & Wallander, 2009; Grey, Boland, Yu, Sullivan-Bolyai, & Tamborlane, 1998; Heisler, 2007; Heisler, Vijan, Makki, & Piette, 2010; Helgeson, et al., 2009; Jacobson et al., 1996; Jones et al., 2008; Toljamo & Hentinen, 2001). For adolescents, this difficulty appears to be increased (Anderson, Brackett, Ho, & Laffel, 1999; Bearman & La Greca, 2002; Betschart, 1999; Burroughs, et al., 1997; Carroll, 2006; Cheung, et al., 2006; Chicoye, Landt, & Rosenbloom, 2002; Davidson, 2004; Dickinson & O'Reilly, 2004; Hains, Berlin, Davies, Parton, & Alemzadeh, 2006; Helgeson, et al., 2009; Laffel et al., 2009; Lehmkuhl et al., 2009; Leonard, Garwick, & Adwan, 2005; Løding, Wold, Skavhaug, & Graue, 2007; Lowes, Eaton, Bill, & Ford, 2007; Maharaj, Daneman, Olmsted, & Rodin, 2004; Moldovanyi & Giordano, 1985; Roemer, 2007; Skinner, Petzing, & Johnston, 1999). The years of adolescence have long been characterized as a time of worsening metabolic control (Anderson, et al., 1999; Dashiff, et al., 2009; Denham, Manoogian, & Schuster, 2007; Dovey-Pearce, et al., 2007; Drew, Berg, & Wiebe, 2010; Greco, Pendley, McDonell, & Reeves, 2001; Helgeson et al., 2010; Løding, et al., 2007; Maharaj, et al., 2004). Indeed, as many as 30-50% of adolescent type 1 diabetes patients are found to be in poor metabolic control (Lehmkuhl et al., 2010). However, despite the extensive documentation of these challenges, answers to the reasons for them have been more difficult to pin down.

A great deal of focus has been devoted to the physiological aspects of management regimens, and some researchers are now arguing that this has been at the expense of other avenues of care. “We have now reached a point where for many the term ‘intensive therapy’ has become synonymous with either multiple daily injections (MDI) or insulin pump therapy, with little or minimal mention of psychosocial support” (Skinner & Cameron, 2010, p. 369). Skinner and Cameron also discuss the intense marketing of new delivery devices such as insulin pens and pumps, without comparable marketing for lifestyle or psychosocial interventions to either patients or their providers (2010). Skinner argues that some results of the Diabetes Control and Complications Trial (DCCT) that led to widespread use of intensive insulin regimens may have been at least partially due to increased support by medical staff involved in the research, Hawthorne effect, placebo or increased belief in ability to achieve goals by the patient (2010). During one study in a Florida diabetes camp, investigators not only showed no correlation between HA1C and the number of daily injections, but also showed a 0.4% increase in HA1C for each type of insulin included in the regime. This led Skinner and Cameron to conclude, “...psychosocial constructs and the support young people receive are better predictors of glycemic outcomes than their insulin regimen.” (2010, p. 372)

The idea that limiting our understanding to pharmacology or technology alone is too narrow a view to be effective has been long and repeatedly established. As Edwall et al. cited in 2008, “To view diabetes from a purely physical standpoint is limiting, if not to say flawed in intervention terms. The management of chronic illness includes psychological, social and emotional aspects and advances in the treatment of diabetes

have conspired to highlight the drawbacks of a purely treatment orientated model of care (Engel 1977, Shillitoe 1988).”

Further, simply providing more information about what daily tasks are necessary to improve control has little effect. Studies both of adults with chronic conditions and younger asthma and obesity patients have shown that, while knowledge is necessary, increased knowledge does not correlate to improved outcomes (Hains, et al., 2006; Knight, 2005; Kyngas, Kroll, & Duffy, 2000). The combination of knowledge with social support and self-efficacy, however, was shown to improve outcomes within a small sample of adolescent asthma patients in Hawaii (Knight, 2005). Other studies have provided evidence linking support, self-efficacy, the patient’s belief in the effectiveness of care, and adherence, although the exact relationships between them remain to be fully clarified (Skinner & Hampson, 1998; Skinner, John, & Hampson, 2000).

#### Balancing Conflicting Needs

One explanation for the disconnect in older adolescents between increasing knowledge and decreasing metabolic control that has received widespread attention and support is the conflict between normal developmental tasks during adolescence and the management tasks associated with diabetes (Lehmkuhl, et al., 2010). Adolescents are experiencing a period of rapid change in their relationships, physical selves, cognitive function, and social behavior (Bokhorst, Sumter, & Westenberg, 2010; Casey, et al., 2009; Guthrie, et al., 1994; Srof, 2006). Among the changes associated with adolescence are the need to increase autonomy from parents and an increased reliance on social relationships outside the family (Beets, Pitetti, & Forlaw, 2007; Bokhorst, et al., 2010;

Burroughs, et al., 1997; Cheung, et al., 2006; Colarossi, 2001; Dovey-Pearce, et al., 2007; Drew, et al., 2010; Greca & Thompson, 1998; Helgeson, et al., 2009). The need to accomplish developmental tasks and still maintain glycemic control have been termed “equal and opposite demands” (Carroll, 2006, p. 251; Lowes, et al., 2007, p. 351). Not only does this conflict interfere with the adolescents’ diabetic management, but it can also impair their psychological well-being: “Normal social development during adolescence requires that a young person begins to reject parental control as they strive to build an integrated self-identity. This involves some rejection of parental and societal controls, with greater attention to peers as a source of rules for ‘normative’ behavior and identity. The presence of diabetes, however, can significantly jeopardize this process...” (Carroll, 2006, p. 244).

The concept of balance in caring for diabetic adolescents is one that appears repeatedly – balance between developmental progress and safety, between independence and familial involvement, between physical and psychological well-being (Ayala & Murphy, 2011; Burroughs, et al., 1997; Dovey-Pearce, et al., 2007; Ingadottir & Halldorsdottir, 2008; Paterson, Thorne, & Dewis, 1998). Paterson et al., in a 1998 meta-synthesis of 43 qualitative studies, found a “healthy balance in life” to be a central theme that far outweighed metabolic control in motivating self care (Ho, Berggren, & Dahlborg-Lyckhage, 2010, p. 260). Investigators looking at quality of life found that metabolic control was not a sufficient predictor (de Dios, Avedillo, Palao, Ortiz, & Agud, 2003; Laffel, et al., 2009). This becomes important because the patient’s perception of their quality of life will impact all aspects of their health: “Adolescents who reported that

diabetes had a larger impact on their quality of life were more likely to believe that management was harder and more upsetting, were less likely to use rebellious coping strategies, had lower diabetes self-efficacy, and had more symptoms of depression” (Grey, et al., 1998, p. 911).

A recurrent theme in literature studying chronic illness, in both adults and adolescents, is the desire for normalcy. This appears in terms of the desire to perceive self as normal, the desire to be perceived by others as normal, and in the ways patients adjust their treatments to make their lives seem as normal as possible. Having a chronic illness such as diabetes impairs the adolescent’s ability to feel normal and creates a feeling of being different (Davidson, 2004; Stewart, Masuda, Letourneau, Anderson, & McGhan, 2011). Conflict with management routines and health care teams arises because, in general, teens do not prioritize their diabetes care above fitting in, and don’t want others to, either (Roemer, 2007). This is not unique to adolescents – researchers studying low rates of dietary adherence in adult women with irritable bowel syndrome found that the desire to be normal was a powerful motivator (Fletcher, Jamieson, Schneider, & Harry, 2008). Nor is this a new idea – as early as 1985 the idea that the “adolescent is an individual first and the disease is only secondary” appears in the literature (Moldovanyi & Giordano, 1985, p. 50).

Simply inundating the patient with warnings and statistics is insufficient – as described previously, knowledge does not equate to adherence. Rather, clinicians must find ways to work within the adolescent’s priorities, which will often place normal social activities at the top. As Dickinson and O’Reilly wrote, “Study participants reported that

being actively involved with the adolescent culture was a priority for them to the extent that diabetes was not necessarily an issue. One participant said, ‘It’s just an extra thing. I tend to think of it as not that big a deal and I just go on... My life comes first – that’s important’ (2004, p. 101). This emphasis on fitting in is also reflected in studies of young people with asthma. Clinicians, however, rarely assess patients’ social support (Stewart, et al., 2011).

As young patients move through their teenage years, their priorities and ability to incorporate their disease shifts. “Striving for normality was not an area referred to by young people in early adolescence but in middle adolescence, young people were described as asserting normality by confronting the limitations imposed by their illness, which sometimes led to rejecting therapy. By late adolescence, views had matured and young people developed a ‘flexible’ adherence so they could get on with life; the disease was not central to this” (Taylor, Gibson, & Franck, 2008, p. 3088). Throughout adolescence, providers need to be conscious of where their patients are on the developmental trajectory in order to work more effectively with them. Teens need to feel that they can implement the management plan within their desired lifestyle in order to effectively adhere to that plan (Davidson, 2004). This includes teaching aimed at family members as well – an article in *Diabetes Self Management* directed at parents emphasized flexibility, teaching management skills away from home, and not barring social activities as keys (Betschart, 1999). This is upheld in a study conducted much more recently, in which patients with higher levels of conflict with same age peers showed worse glycemic control, as did patients with more negative emotions associated

with diabetes – researchers recommended interventions that include same age peers or are directed at relationships (Helgeson, et al., 2010).

Once again, finding the balanced lifestyle between the patient’s metabolic and psychosocial needs appears to be the holy grail of diabetes research. Understanding how to achieve this balance, however, has been elusive. Studying the patients’ perspective has shown that the teenagers themselves generally understand the need for balance and strive for it, but find it difficult to achieve (Davidson, 2004). Interestingly, one study, in which investigators interviewed healthcare professionals working with adolescents with diabetes, found that participants understood the importance of tailoring interventions to fit into teens’ lives but found difficulty doing so within the limited resources available in a clinic setting (Spencer, 2011).

Overall, because of the unique developmental needs of the adolescent population, more understanding of the psychosocial milieu and its impact on diabetes management is necessary. As Srof points out, “In essence, the interpersonal influence should receive greater attention in research. Teens may be especially vulnerable to negative environment influences. Concurrently, the positive influences may play a much more important role in teens than in adults” (2006, p. 372). This view was put forward in 1999 by Skinner et al. as well, calling for more understanding of the adolescent social context.

### The Importance of Social Support

La Greca and Thompson refer to an “unfortunate tendency” to view the patient’s friends as obstacles (Greca & Thompson, 1998, p. 102). Newer research has found the

issue to be more nuanced, with friends providing both positive and negative influences on adherence. Citing several studies that included both adolescent and adult patients, Ingadottir & Halldorsdottir wrote “Support is an important part of the lived experience of chronic illness. It can be either informal or formal, with family, friends, and health care professionals playing an important role with accepting, responsive, and person-centered relationships providing optimal conditions for good adherence” (Ingadottir & Halldorsdottir, 2008, p. 608).

### Developmental Considerations

In a 2008 review of literature, Taylor, Gibson and Franck found that in 12 of 20 studies, “being with friends and gaining their acceptance was found to be the most important aspect of a young person’s life”(p. 3085). Increasing time away from parents and more time with peers and in school activities means the adolescent must make more decisions about his or her own care (Leonard, et al., 2005). This also increases the opportunities for influence by peers.

The literature on developmental changes in peer and family relationships underlines the importance of clearly delineating different developmental stages. Many studies of adolescents included younger children or adults, “which failed to take the developmental challenges of adolescence into consideration.” (Taylor, et al., 2008, p. 3090). As an example of why this is not useful, in one study reviewed children ages 8-10 showed equal support between friends and parents, but by 16-18 parents were rated as lower sources of support than friends (Bokhorst, et al., 2010).

### Impact of Diabetes on Social Relationships

“Clearly, fundamental conflicts exist between the tasks of managing diabetes and the normative developmental tasks facing the young adolescent – striving to be comfortable with a rapidly maturing body, defining an identity, establishing a new role in the family, and gaining positive acceptance by peers” (Anderson, et al., 1999, p. 713). As early as 1985, studies cited fears among adolescents regarding the reaction of friends and potential friends to their diabetes (Moldovanyi & Giordano, 1985). These fears are often linked to the adolescent tendency to compare themselves to their friends and desire to be viewed as normal (Huus & Enskar, 2004).

Results regarding how adolescent diabetes patients view the impact of their diagnosis on their social relationships have shown some variance, at least partially because such research has been limited (Taylor, et al., 2008). Taylor et al. found that “Young people with chronic illness generally view themselves and their lives in the same way as their healthy peers,” but these same young people also feel their illness is a barrier to forming friendships (2008, p. 3090). Some research has upheld their perception, finding that friendships may indeed be more difficult to form for young people with diabetes (Helgeson, Reynolds, Escobar, Siminerio, & Becker, 2007). Other studies, however, have had contradictory results.

In two studies conducted in the 1990s, researchers found no difference in social competence between adolescent diabetes patients and same-age peers (Bawden, Stokes, Camfield, Camfield, & Salisbury, 1998; Nassau & Drotar, 1995). Another study of young adults (age 19-26), who had been followed for 10 yrs following diagnosis, showed

less friends overall than same age peers, but similar numbers of close friends and love relationships (Jacobson, et al., 1996). The diabetic participants did, however, demonstrate less trust and closeness in romantic relationships (Jacobson, et al., 1996). More recently, a researchers studying “adolescents” aged 10.7 to 14.21 years found that diabetic participants were equally likely to have a best friend as healthy participants (Helgeson, et al., 2007). Female diabetics, however, did show less of an increase in support over time as compared to healthy adolescents (2007).

In a 2004 study of adolescent diabetes patients, investigators found some examples of how participants felt their friendships were impacted by their diabetes:

Some participants discussed whether to let friends into their world of living with diabetes. Friends are an invaluable part of the adolescent experience, and all of the study participants talked about how much they appreciated when their friends were caring and supportive about their diabetes. They felt comforted knowing that their friends were interested in learning about diabetes. Friends showed their interest and concern by asking questions and offering to help. On the other hand, however, some participants reported times when it seemed that friends forgot about their having diabetes because they did insensitive things such as offering candy or eating at inappropriate times. (Dickinson & O'Reilly, 2004, p. 104)

One reason for inconsistent results has been inconsistent methods. For example, one group of researchers stated that young diabetic patients had lower psychosocial functioning than same-age peers, but this was based on evaluating the parents' perceptions (Laffel, et al., 2009). This is a problem because previous work has shown that “...parents were often inaccurate at predicting their child's peer relationships” (Bawden, et al., 1998, p. 667).

An area that does have consistent results is the impact of diabetes in terms of time and planning. Adolescent diabetes patients report increased demands because their

diagnosis requires planning ahead for activities and provides less freedom than they perceive exists for their friends (Huus & Enskar, 2004). Both patients and same age friends report time taken from social activities as one of biggest problems with diabetes (Lehmkuhl, et al., 2009). The slowed rate of increase in social support for diabetes patients when compared to healthy same age peers was attributed by the authors to the impact diabetes care has on time spent with friends (Helgeson, et al., 2007).

Another impact of diabetes on adolescents is that they are forced by their disease to have increased interactions with adult authority figures such as teachers, school nurses and healthcare providers. These interactions may or may not be positive and can, either way, contribute to the feeling of being different from peers (Dickinson & O'Reilly, 2004). Adolescence is a developmental period during which difference is viewed as negative, and shows of concern by friends, teachers may be viewed as stigmatizing (Dovey-Pearce, et al., 2007). Further, there is conflict that occurs between the independence needed by adolescent patients and need for parental involvement to maintain metabolic control (Hanna & Guthrie, 2001). These forced relationships result in decreased feelings of autonomy, perhaps because adolescents report being treated differently by parents, friends and teachers (Burroughs, et al., 1997; Dickinson & O'Reilly, 2004; Huus & Enskar, 2004). Adolescents sometimes view this extra attention as supportive, but frequently feel nagged (Huus & Enskar, 2004).

### Impact of Social Pressures on Diabetes Management

Studies of adults have come down largely in favor of social support. Patients showing higher levels of family and friend support tend to have improved self care

behaviors (McDonald, Wykle, Misra, Suwonnaroop, & Burant, 2002; Toljamo & Hentinen, 2001; Wang & Fenske, 1996). More recently, “Higher levels of social support – especially illness-specific or regimen-specific support – are associated with better diabetes and other illness self-management” (Heisler, 2009, p. 123). A more specific investigation linked friend and family support some aspects of adherence, including glucose monitoring and meal plan adherence in Latino and African American patients (Rosland et al., 2008).

Support has been positively linked to adherence in the adolescent population as well. For example, impairment in several domains affecting self-concept, including formation of close friendships, is associated with poor metabolic control in adolescent girls (Maharaj, et al., 2004). The relationship, however, between support and diabetes management is not always as clear in the adolescent patient. This clarity may improve in the future with recent work on creating instrumentation specifically designed for this population (Fernandes, Wales, Crisp, & Kyngas, 2011).

Teenagers with diabetes have been found to have higher problem solving skills across ages 8-17, which would intuitively correlate to improved adherence but, in fact, did not (Thomas, et al., 1997). This is because normal development socially works against using these skills in social situations – the drive to be like or please one’s peers in the adolescent age group outweighs the drive to use these skills (Burroughs, et al., 1997; Thomas, et al., 1997). Thomas’ study is of special interest despite its age because results were compared and found to be consistent between urban and rural samples (Thomas, et al., 1997). In another study from the same time, examining the Diabetes Control and

Complications Trial, researchers found that “older adolescents with the strongest self concepts, the most social support, the most knowledge about IDDM, and the fewest life stressors adhered the least well and had the poorest metabolic control. The youths who were theoretically the best equipped to adhere to their regimens were performing the worst” (Burroughs, et al., 1997, p. 444). On the other hand, in an article in *Patient Care for the Nurse Practitioner*, authors claimed, “In general, an adolescent who is active, gets along with parents and friends and performs successfully in school will usually rise to the challenges diabetes presents. Conversely, a teen who ignores school assignments, functions poorly on the social front, and fights with parents is more likely to have poorly controlled diabetes” (Chicoye, et al., 2002).

The desire to fit in and avoid being viewed as different from same age peers can impair adolescents’ adherence to recommended behaviors. For example, “many children resent wearing medical-alert identification because they feel it makes them visibly ‘different,’” despite the fact that wearing such identification is highly recommended for their own safety (Ayala & Murphy, 2011, pp. 50-51). In other instances, adolescents’ feelings of embarrassment and difference related to using equipment such as insulin pumps might lead them to avoid their use, even when the adolescent expresses understanding that using their equipment consistently would help them feel better (Huus & Enskar, 2004).

### Psychological Impacts

Adolescents are particularly vulnerable to mental health problems, specifically depression and low self-esteem (Colarossi & Eccles, 2003) . Adding a chronic diagnosis

compounds this vulnerability. For one thing, the presence of or potential for lifelong disease and life threatening or long term complications forces patients to contemplate their mortality sooner than normal (Dovey-Pearce, et al., 2007). In an in-depth case study following a 26 year old woman diagnosed at age 10 with type 1 diabetes, Tilden noted the profound impact the disease can have on a person's psychological well-being (2005).

Diabetes patients have, in some of the literature, shown an increased incidence of psychological disorders, eating disorders and substance abuse (Kakleas, Kandyla, Karayianni, & Karavanaki, 2009). Adolescent girls, in particular, experience disruptions in body image – possibly because insulin therapy often causes weight gain (Kakleas, et al., 2009). Some researchers have found an increased risk of depression, perhaps as high as 1 in 7 (Ayala & Murphy, 2011). Others agree that adolescents with diabetes may have more tendencies toward depression and anxiety, but point out that much of the research in the last decade has been inconsistent and care must be taken before generalizing the results (Helgeson, et al., 2009).

Some of this increased vulnerability may also relate to negative impacts of diabetes on social situations. Storch, in a study of children ages 8-18, found that those with diabetes were subject to higher rates of bullying and lower rates of positive support from others their own age (2004). Further, these negative interactions were correlated with depressive symptoms and social anxiety (Storch, 2004). Further examination of negative social interaction will be discussed in a later section.

Diabetes may also impact normal development and self-concept: “A chronic illness such as diabetes may interfere with successful individuation among

adolescents”(Maharaj, et al., 2004, p. 710). Seiffge-Krenke conducted a four year longitudinal study starting at age 13 using a self-report questionnaire rating achievement of developmental tasks. Adolescents with diabetes rated themselves in lower than same age peers in perceived physical maturity and individual lifestyle, although the differences diminished over course of the study. Interestingly, diabetes patients and healthy adolescents started at the same level in self-perceived occupational competence, but the diabetes group gained more. Also of note, responses to the questionnaires showed no impact from length of diagnosis or metabolic control (1998).

While adolescents with a chronic diagnosis demonstrate increased psychosocial vulnerability, problems are not inevitable (Dovey-Pearce, et al., 2007). Social support has been linked to improved mental health both during adolescence and in adults (Colarossi, 2001; Colarossi & Eccles, 2003; Ho, et al., 2010). Further, same age peer support has been shown to be a significant predictor of depression in teens with diabetes (Skinner & Hampson, 1998). The protective effect of positive social support may be more profound in younger patients than in adults, and both increased the vulnerability to mental health issues among adolescents and the protective effects of support may be stronger for girls (Colarossi & Eccles, 2003; Dovey-Pearce, et al., 2007).

Positive social support seems to have a buffering effect on the negative psychological impacts of diabetes, but the exact mechanism has not been determined. At one point, “Varni and colleagues found that while family support is predictive of psychological adaptation in children with IDDM, only the youth’s perception of support from their peers is predictive of adaptation during adolescence” (Burroughs, et al., 1997,

p. 441). Further investigation, however, suggested that the relationship may be indirect – social support was found to impact stress, which in turn impacted well-being, but no direct relationship was found between support and adjustment (Malik & Koot, 2009). Malik and Koot did acknowledge that, despite the lack of a direct connection, social support has been found to be positively correlated with positive adjustment, and lack of it has been linked to increased distress (Malik & Koot, 2009). Support was found to have a relationship with both self-esteem and social competence in the general adolescent population, but the nature of the relationship was unclear, perhaps due to complexity of modeling “social support” (Wilburn & Smith, 2009).

Negative forms of social interaction, however, are of equal import to the psychosocial well-being of adolescent patients. While it may be easy for clinicians and parents to regard friction with same age peers as a normal part of the adolescent period, “Difficulties with peers should be considered a potentially important source of stress that can affect diabetes-related outcomes” (Helgeson, et al., 2007, p. 42). Negative relations with peers have been linked to both diminished psychological health and decreased metabolic control (Helgeson, et al., 2007). Social support has been shown repeatedly to impact stress, which, in turn, affects both metabolic control and general well-being (Hanson, Henggeler, & Burghen, 1987; Malik & Koot, 2009).

Finally, there is some evidence that both social and family supports are vital, but their impact becomes measurable only under certain circumstances. Tusaie, Pusker and Sereika found that adolescents’ psychosocial resilience was positively impacted by social support, but that social support only became a measurable factor as age and number of

negative life events increased (Tusaie, Puskar, & Sereika, 2007). Friend support was an important factor, but friend support could not substitute completely for family support (Tusaie, et al., 2007).

### Physical Activity

Research investigating the link between support and physical activity is included here both because exercise is part of the recommended diabetes self-management regimen for both type 1 and type 2 diabetics and because it is a useful example of a health promoting lifestyle change. Investigations of physical activity with a focus based on Pender's Health Promotion Model will be addressed in a later section.

Physical activity tends to decline during the adolescent years (Casey, et al., 2009). Much research has been devoted to understanding why, and to interventions to counter this trend. Same age peer support was found to be a strong predictor of physical activity among adolescent girls (Dunton, Schneider, & Cooper, 2007). Investigation into how same age peers might affect activity behavior found a connection between social support and self-efficacy, specifically that related to overcoming barriers to physical activity in teenage girls (Beets, et al., 2007). The study by Beets et al. also found no relationship between parent support and physical activity (2007).

La Greca et al., as quoted in Bearman & La Greca, found that friends provide emotional support for physical activity (2002). This was correlated later by Casey et al., who found that being with friends and having fun together showed a positive impact on physical activity (2009). This is consistent with findings, discussed under Types of Support, that social support in diabetes from friends tends to be of the emotional type.

### Relationships Between Friend and Family Support

It should be acknowledged that family and friend support do not exist in isolation from one another. As early as 1989, researchers found that the combination of high levels of friend and family support correlated with reduced adjustment problems in chronically ill and disabled youth, but high levels in one and low in the other did not (Wallander & Varni, 1989). Interdependence between friend and family support was upheld more than ten years later, when Colarossi found that family and same age peer support can build on, but not replace, each other (2001). Further, adolescents with friends who are involved and supportive tend to have less conflict with parents as they increase independence (Huus & Enskar, 2004).

Herzer et al. sought to clarify the nature of the links between family and friend support in a 2009 study, in which they examined whether the theory of cross-buffering social support developed in work with adults could be applied to adolescent patients. Cross buffering suggests that support from one area of the social network offsets negative or lacking support in another, which would seem to contradict some prior results with teenagers (Herzer, et al., 2009). Herzer et al. found that friend support partially mediated negative effects of ineffective parental support, but not vice versa: "...among chronically ill children and adolescents, friendships are especially important for quality of life, self-esteem, and overall emotional/behavioral functioning. When these relationships are strained or lacking, there seems to be little in the way of support from parents that can make up for peer rejection" (Herzer, et al., 2009, p. 506). However, parental support was still shown to be a stronger independent predictor of well-being (Herzer, et al., 2009).

### Types of Support

Social support is generally divided into four categories: emotional, appraisal, informational and tangible (Vandam, et al., 2005). Family most often provides tangible and emotional support, while friends are more likely to focus on emotional support, often in the form of companionship (Cheung, et al., 2006; Greca & Thompson, 1998; Helgeson, et al., 2009; Karlsson, 2008; Lowes, et al., 2007; Malik & Koot, 2009; Skinner, et al., 1999). The impact of social support may increase as the intensity of the adolescents' treatment regimen increases (Skinner, et al., 1999). This is interesting because, in one 2009 study, researchers found that friend support is rarely specific to diabetes treatment behaviors, such as testing blood glucose or remembering injections (Kakleas, et al., 2009). Another group of investigators found that emotional support and support for exercise or testing were the most frequent forms of support reported, but that weekly instances of these forms of support was rated a very high frequency among those sampled (Bearman & La Greca, 2002). There may be an indication for looking into increasing behavior specific support, however, as there is evidence of a correlation between the presence of support for testing and adherence (Bearman & La Greca, 2002; Kakleas, et al., 2009). Further, training for friends in relation to diabetes self care may be further beneficial as Kakleas et al. found that same age peers may lack knowledge for effective support and may even have a negative influence on the patient's self care (2009).

Emotional support may have an impact as well, although it has been harder to quantify in the literature. Adults have reported that "...gestures from friends that

signified caring reinforced the importance of caring for oneself” (Maclean, 1991, p. 693). Similarly, adolescents interviewed reported that “emotional support from peers made it easier to integrate diabetes into the teenagers’ everyday life” (Karlsson, 2008, p. 568). Caring, demonstrated through friends’ modifying their own behavior (e.g. not eating sugary foods when spending time with the patient), was also reported as helpful (Kyngas, Hentinen, & Barlow, 1998).

A last effect of emotional support that bears mentioning is that adolescents’ use of more formal networks may be impacted by friends. In an investigation of methods used by teens to reduce or cease alcohol consumption, researchers found not only was turning to informal supports (e.g. friends) for help effective, it also made them twice as likely to seek out professional sources of help (Metrik, Frissell, McCarthy, D’Amico, & Brown, 2003). In teens with diabetes, this may be relevant due to the high level of interaction with healthcare professionals necessitated by their condition.

### Safety

One point of interest that surfaced in a few studies was the use of knowledgeable friends to improve safety and feelings of security when patients were away from home. In one study, teens did not see diabetes as taking priority in social situations, and most had 3-6 best friends who they regarded as supportive, helpful, and who “looked out for them” (Lowes, et al., 2007, p. 352). When friends are prepared to assist during a hypoglycemic episode, for example, these friends are regarded as a safety net who can provide help if adolescents need it (Carroll, 2006; Davidson, 2004; "Erratum," 2004; Karlsson, 2008; Viklund & Wikblad, 2009). Some participants even reported feeling as

though they could forget about their diabetes when in the company of friends who knew how to help in the event he or she had trouble (Karlsson, 2008).

### Disclosure

Diabetes is not a diagnosis that alters a person's outward appearance. Patients who have diabetes are, therefore, "outed" to various degrees by behaviors – changes in diet, injections, checking blood sugars. The decision whether to disclose their diagnosis to those around them or to try to hide it may affect the patient's level of adherence. The decision to disclose is likely affected by reactions of healthy same age peers and the fear of a stigma attached to a condition. For example, in a 1999 study by Faro, as cited in Cheung et al., researchers found that "almost of third of the sample stated they needed to explain to nondiabetic peers that diabetes was not contagious"(Cheung, et al., 2006, p. 54). In a 2008 study, Mulvaney et al. found that adolescents with type 2 diabetes were hesitant to tell friends about their diabetes because of the misperceptions that diabetes is contagious (LeClair, Marquis, Villalon, & Strychar, 2009).

In a study of 130 healthy adolescents in grades 5, 8 and 10, investigators found that the most common responses to questions regarding the cause of diabetes in young people were heredity, age, physical inactivity, obesity, and poor diet (LeClair, et al., 2009). The authors commented that these last three were misconceptions, especially with regard to Type 1 diabetes, that might negatively affect treatment of same age peers with the condition (2009). Also worthy of note, the inaccurate belief that diabetes is contagious did appear, but only 3 times and only among the youngest grade sampled

(LeClair, et al., 2009). This may indicate that the fear of this misconception is more prevalent than the misconception itself, although no research has directly compared them.

Most adolescents tend to tell most of their friends (Hains, et al., 2006).

Adolescents have reported having close friends who know about their disease as important (Davidson, 2004). Some, however, expressed a sense of being unsure when and to whom to disclose their diabetes, and some even expressed regret about past disclosures because of changes in relationships or worries it caused other teens (Davidson, 2004). Reactions to disclosure vary and may be either positive or negative – it is therefore highly important that patient has control over when and to whom disclosure of their diagnosis takes place (Dovey-Pearce, et al., 2007). There is evidence, however, of a correlation between the number of friends a patient plans to tell at their initial diagnosis and adherence – so encouragement to disclose may be in a patient’s best interest (Wysocki & Greco, 2006).

### Gender Differences

The literature does show some differences between male and female adolescents in both how much support they perceive from friends and the nature of that support. Girls report intimacy and emotional support from social contacts more frequently than boys (Bearman & La Greca, 2002). With regards to where adolescents receive their support, “Female adolescents reported greater numbers of supportive friends than supportive adults, they perceived more support from these friends than they did from adults, and they were more satisfied with support from friends than support from adults... Male adolescents, on the other hand, reported similar numbers of peer and adult

supporters. They reported more frequent support from adults than friends but were more satisfied with friendship support than parental support” (Colarossi, 2001, pp. 237-239) Colarossi confirmed two years later that girls receive more support from peers, while boys tend to rely on family more (Colarossi & Eccles, 2003).

Returning for a moment to the issue of disclosure, girls are highly likely to both tell friends about their diabetes and believe “...these friends had a basic understanding of diabetes, which was usually dependent upon information provided by the teenagers themselves” (Lowes, et al., 2007, p. 352). This finding contradicts a study three years earlier, in which researchers found girls understood the importance of telling others for safety, but did not do so consistently and often found the need to do so frustrating (Dickinson & O'Reilly, 2004).

One more difference between male and female adolescents is that girls rate their close friendships as more supportive (Rueger, Malecki, & Demaray, 2008). There was, however, no correlation found between this increased support in girls and either conduct or social competence. In fact, “Adolescent girls have a higher tendency to mismanage their diabetes than boys and have worse metabolic control and more symptoms of depression and anxiety than boys” (Dickinson & O'Reilly, 2004, p. 100). Researchers posited that this may have been partially because there is little variation between patients in the scores they assign their friends – they tend to rate the supportiveness of friends as high across the board (Rueger, et al., 2008). Another explanation may be because of variation in those behaviors encouraged by peer groups – girls may be more susceptible to negative peer influence (Rueger, et al., 2008)

### Negative Support

Support from friends is positively perceived overall (Carroll, 2006; Karlsson, 2008). However, there is evidence that certain types of social support can have negative impacts on patients' psychological or physical well-being. These negative impacts can range from peer pressure that reduces adherence or interference in daily life from excessive expressions of concern to outright teasing. In a 1991 study of adult diabetes patients, Maclean received reports of "unwanted attention," social stigma, being self-conscious about eating differently from others, feeling singled out, and feeling that diabetes was too personal to share with most people (1991).

These results are borne out in the adolescent population, as is shown in the following.

Peer Pressure. As discussed above, normalcy and fitting in with peer groups are major influences on adolescent behavior. When self-care conflicts with fitting in with friends, friends often win (Kyngas, et al., 1998). Adolescents' health promotion tends to be in line with peer groups – thus adolescents with DM who have friends who are likely to exercise and make healthy food choices have better adherence and vice versa.(Greca & Thompson, 1998). Friends may provide "negative influences" (Cheung, et al., 2006, p. 56). In teenagers with chronic health conditions, these effects may be magnified, as well as posing a threat to metabolic control:

The study findings illustrate that perceived social acceptance among girls is associated with higher HbA1c. This is consistent with previous research, which has demonstrated significant links between popularity among girls and poorer metabolic control. Strivings for social acceptance may be problematic for girls with a chronic medical illness such as

diabetes, which makes them feel “different” from their nondiabetic peers. Vulnerable girls who seek social acceptance and connection may be more likely to conform to social pressures to engage in behaviors that may adversely impact metabolic control. (Maharaj, et al., 2004, p. 713)

These results were upheld by a later study in which adolescents who seek advice and support from their peers to a greater degree than their parents were shown to be at increased risk for less effective management and for placing acceptance above health (Drew, et al., 2010). In another instance, perceptions of peer support by adolescents increased with age, but no correlation was found between support and metabolic control – the researchers in this case posited that this lack of correlation was because there was not enough data on the nature of this “support” (Pendley et al., 2002).

The social environment of an adolescent may be further complicated by friends who do not understand their condition. As Lowes et al. wrote, “if peers lack knowledge about diabetes and, consequently, place little importance on its management, their support may be detrimental and even encourage non-adherent behavior” (2007, p. 351). This also complicates investigation into friend support, because an adolescent may rate the support of such friends highly even though it is impairing their metabolic control.

Nagging and Interference. Even well-intentioned, knowledgeable friends can sometimes provide forms of support that actually have a negative impact. Excessive attempts to encourage adherence or assist with self care may be seen as intrusive or nagging (Davidson, 2004; Vandam, et al., 2005). For example, one participant in Carroll & Marrero’s study mentioned her best friend behaving like her mother (2006). Another study showed that adolescents viewed as unfavorable friends supporting insulin injections and food choices (Bearman & La Greca, 2002). In other cases, excessive interference

may create a sense of dependence (Vandam, et al., 2005). Either way, such negatively perceived interactions may be associated with less desirable outcomes (Vandam, et al., 2005). At the very least, many adolescents are annoyed by having to answer frequent questions about their disease and management regimen from their peers (Carroll, 2006). As Dickinson and O'Reilly found in studying a group of female adolescent patients, "...these young women felt that living with diabetes was no big deal, and they wanted others, including parents, friends, teachers, and school nurses to treat it that way as well." (2004, p. 105)

Unwanted Attention. Dickinson and O'Reilly found that adolescent girls experienced "unwanted attention" due to their disease and sometimes found others making a "big deal" of their diabetes embarrassing (2004, p. 102). In another study of adolescents, "Most admitted to concealing care issues around peers to avoid having added attention called to them concerning their diabetes" (Davidson, 2004, p. 77). Still others had negative experiences with friends who might disclose the patient's diabetes to others or ask embarrassing questions in public (Davidson, 2004).

Reinforcing the conflicting nature of research into the adolescent population, researchers comparing participants in diabetes camp with non-camping same age peers found very different results: "More than 50% of the respondents from both the AC [camping] and NC [non-campers] groups never or very seldom felt embarrassed dealing with diabetes in public. More than 50% reported they never find diabetes limiting their social relationships or friendships. Sixty percent responded they frequently had to explain the meaning of diabetes to others. Sixty percent of respondents in the AC group

and 80% in the NC group reported they feel good about themselves often or all the time.” (Cheung, et al., 2006, p. 56)

Negative Reactions. Perhaps one of the biggest concerns for teenage diabetes patients is outright negative reactions to their condition or management behaviors, such as injecting insulin. Hains et. al found that adolescents reported following their care regimens in social contexts as being more difficult due to fear of negative reactions by friends (2007). This data built upon findings by the same researcher that these patients’ apprehension about being labeled different or singled out in negative ways reduced their adherence, even though such a reaction was not likely (Hains, et al., 2006).

While direct negative reactions do not occur as frequently as the patient’s perceptions would indicate, misconceptions or misinterpretations by classmates or same age peers can still pose a threat to the adolescents’ psychological well-being. Some experience misunderstandings from classmates, such as that they are lucky to skip class when their blood sugar is low (Carroll, 2006). Behaviors that require needles – injecting insulin and testing blood glucose – seem to pose a particular problem. This is not unique to adolescents – in adults, people going on insulin for the first time reported feeling like drug users or somehow less normal (Morris, Povey, & Street, 2005). In a rare documentation of specific negative experiences, Skinner et al. wrote about teens who reported being called “druggie” by same age peers and one young person who was asked to step outside to inject during a camping trip (Skinner, et al., 1999).

Despite being far from guaranteed, negative reactions can have significant detrimental impacts when they do occur. Negative peer reactions can include avoidance,

teasing, or exclusion, and problems with same age peers is a major factor influencing self-esteem and well-being in young patients with chronic illness (Herzer, et al., 2009). Physical activity can be inhibited by friends' teasing, and increased levels of conflict are associated with decreases in self-care (Casey, et al., 2009; Helgeson, et al., 2009).

Finally, it is worth noting that some adolescents who are already at risk for decreased levels of care are also less likely to be receiving effective, positive social support. Low income adolescents were much more likely to report they received no support from friends or that friends did not know about their diabetes (Greca & Thompson, 1998). These findings were consistent across patients from Caucasian, Hispanic and African-American backgrounds(Greca & Thompson, 1998).

### Peer Support

A major area of investigation with both adolescents and health promotion is the effect of support by peers. As early as 1985, Kaplan, Chadwick and Schimmel discussed the disappointing impact of purely educational interventions and showed that peer modeling had more promise (Kaplan, Chadwick, & Schimmel, 1985). More recently, the benefits of peer support were discussed by Vandam et al., who wrote, "Social support from peers and fellow patients, both in group consultations, peer group sessions, telephone peer contacts, or Internet-based peer communication, may enhance lifestyle adjustments and outcomes of care" (2005, pp. 8-9). Understanding the impact of peer support is necessary to this research because adolescents cite having support from friends with the same condition and friends who are unaffected as both being important (Kyngas, 2004).

Support from peers has great promise for improving self care behavior (Brownson & Heisler, 2009). “Peers have led to improved patient outcomes through their role in enhancing linkages to clinical care, providing an individualized approach to assessment and treatment, assisting in patient-centered collaborative goal setting, education and skills training, ongoing follow-up and support, and linkage to community resources. Continuing to develop and evaluate innovative models for more effectively mobilizing and integrating peers into diabetes care has great potential for improving diabetes outcomes worldwide” (Brownson & Heisler, 2009).

Peers provide models of behavior, demonstrating to patients how to apply management strategies to real world situations and encouraging them to believe they can make positive changes (Cudney, et al., 2005; Ho, et al., 2010; Hughes, et al., 2009; Maclean, 1991; Teerarungsikul et al., 2009). Investigators dealing specifically with adolescents found that meeting others who have experienced similar problems can provide teens with both inspiration and models for improved problem solving (Davidson, 2004; Viklund & Wikblad, 2009). Peer support reduces the patient’s sense of isolation and fear and is seen as positive by recipients (Hughes, et al., 2009; Sumner, Gillet, & Harper, 2001). Ninety percent of chronic renal patients reported that a peer support service was a positive experience, with specific benefits cited including information, encouragement, reassurance, and help making treatment decisions (Hughes, et al., 2009). Peer support has also been shown to reduce health care costs, providing a feasible way to improve patient outcomes and reduce emergency service usage without the additional

cost of, for example, one on one nursing interventions (Heisler, 2005, 2007; Wagner et al., 2001).

Peer support not only benefits the recipient; it has been shown to have benefits for the supporter as well (Dale, Caramlau, Sturt, Friede, & Walker, 2009; Dale, Caramlau, Lindenmeyer, & Williams, 2008; Heisler, 2005, 2007, 2009; Sandra L. MacPherson, Dayle Joseph, & Sullivan, 2004). More specifically, “Individuals who provide social support through volunteering experience less depression, have heightened self-esteem and self-efficacy, and improved quality of life, even after adjusting for baseline health status and socioeconomic status. Furthermore, providing support to others can lead to improved health behaviours on the part of the helper, decreased mortality risk, and improved health outcomes and function” (Heisler, 2009, p. i23).

The mutual benefits of peer support become especially interesting when educational interventions using patients as experts are taken into account. Payne, in a 1995 literature review of the use of group learning for patients with chronic illness, described the evidence of its advantages as “overwhelming” (1995, p. 270). Diabetes education sessions delivered by high school students to fifth graders showed significant increases in the students’ knowledge (Coleman et al., 2010).

A discussion of peer support among adolescent diabetics must include the impact of camps geared toward youth with diabetes. Teasing out the precise impact is challenging because many studies of adolescent diabetics take place at these camps. For example, Cheung et. al studied the relationship of “social support” on quality of life in adolescents who attended diabetes camp versus those who did not – blurring the line

between intentional peer support versus more generalized social support (Cheung, et al., 2006). In two studies, however, researchers discussed camp specifically. In 1990, attempts to establish teen peer support group were unsuccessful until using a camp weekend created a common experience (Crowe & Billingsley, 1990). Later, investigators showed that adolescents develop strong social networks during diabetes camps (Cheung, et al., 2006). This is reinforced by other researchers' findings that peers who are more similar tend to offer more effective support, particularly in regard to age (Brownson & Heisler, 2009; Heisler, et al., 2010).

### Physical Activity

The Move More program used community based social marketing techniques in a rural, economically depressed area to recruit diabetes patients into a program that included increased physical activity and peer support from trained Lay Health Educators (Richert, Webb, Morse, O'Toole, & Brownson, 2007). Of note is that this program resulted in increased physical activity among participants, and that communication between participants and the Lay Health Educators included face to face as well as online interactions (Richert, et al., 2007). Two years later, peer support in the form of group dance classes improved physical activity among female African American participants, who highlighted camaraderie and shared enjoyment as reducing barriers to exercise (Murrock, Higgins, & Killion, 2009).

### Rural Issues

Community based peer support may be especially important in areas where “patients have difficulty accessing care within traditional health care settings” (Clark, 2008, p. 117). One group of researchers saw some success improving the diabetes care of Hispanic migrant workers using Lay Health Advisors within the population (Heuer, Lausch, & Bergland, 2006). Two more used community based programs to increase both understanding of and compliance with diabetes management regimens in American Indian communities, citing the patients’ increased ownership over their care and culturally appropriate instruction as major factors in their improvement (Mendenhall et al., 2010; Struthers, Hodge, De Cora, & Geishirt-Cantrell, 2003).

### Technology Based Interventions

Positive results have been shown with both face to face and technology based interventions (Heisler, 2007). Investigations of telephone and internet based support have both shown promise, with both subjective and objective benefits linked to remote peer support (Cudney, et al., 2005; Lehmkuhl, et al., 2010; Vandam, et al., 2005). The results of investigations of technology based support have been somewhat inconsistent to this point, but many of the researchers expressed optimism regarding their potential as further understanding is developed (Andersson, Ljótsson, & Weise, 2011; Dale, et al., 2009; Glasgow, 2003; Jennings, Powell, Armstrong, Sturt, & Dale, 2009). This avenue of intervention is worthy of further investigation if for no other reason than its relative popularity - over 60% of type 2 diabetes patients expressed willingness to participate in web-based intervention (McKay, Glasgow, Feil, Boles, & Barrera, 2002).

Patients using discussion boards online report that they gain both information for self-management and a sense of being understood that non-diabetic friends and family had no way of providing (Armstrong & Powell, 2009). Also of note - this study did not bear out concerns voiced by professionals about incorrect or misleading information – if misinformation was posted, it was quickly corrected by others. However, the patients in this study were “expert” patients and it may not be a representative sample (Armstrong & Powell, 2009). This upheld results from a previous study in which “...in over 3,146 patient messages [on online discussion boards], we did not observe a single instance of information or advice being given by participants that was dangerous or contained serious misinformation.” (McKay, et al., 2002, p. 44).

Overall, patients report high levels of satisfaction with telephone and online supports (Dale, et al., 2009). One telephone intervention showed equivalent satisfaction in peer support versus nurse support, but no metabolic indicators of improvement were found. Poor targeting of the intervention was presented as a possible explanation (Dale, et al., 2009). The theme of promising but inconclusive was upheld by two more intervention studies for type 1 diabetes patients including adolescents (Lehmkuhl, et al., 2010; Nordfeldt, Hanberger, & Berterö, 2010)

With regard specifically to adolescents, interviews with teenagers cited texting and online chat as important parts of their support networks because these allow them to freely share anonymously (Kyngas, 2004). A 2008 article in *Diabetes Self Management* listing online support resources included fourteen online peer support forums, including one specifically for teens (Phillips, 2008). Several of these resources contain a heavy

advertising component, but they do allow adolescents to share experiences about how their diabetes affects things like dating and friendships (Phillips, 2008).

### Potential Issues

There are potential issues, both with peer support and attempts to study it. First, it is very important that peer mentors be fully prepared for their roles. In one peer intervention, two out of 20 patients reported negative experiences that included being made more anxious by the peer supporter (Hughes, et al., 2009). The authors speculated that this could be due either to misinterpretation of the level of information desired by those receiving mentorship, or that these two patients had felt compelled to participate in the program rather than volunteering (Hughes, et al., 2009). There is also concern regarding how to target research in a way that will provide the clearest insight. For example, the clinical impact of peer support was inconclusive in a recent study; the authors wondered whether the lack of detectable improvement was because few studies have targeted those with poor control to begin with (Smith et al., 2011).

A recent Cochrane review summarized, writing, “Peer support is a complex phenomenon and poor reporting of the exact nature of the support provided in these studies posed challenges in the interpretation of their elements key to achieving effective peer support” (Dale, et al., 2008, p. 20). Dale et al. also go on to provide guidance for further intervention and study: “emotional and/or appraisal peer telephone support may need to be combined with informational support to have a beneficial effect on more complex health behavioral changes... Informational support appears likely to require

tailoring to individual and local circumstances, and a peer may be much better placed to achieve this than a lay person” (J. Dale, et al., 2008, p. 20).

### Interventions

The need for interventions that take into account developmental needs has been long established (Massouh, Steele, Alseth, & Diekmann, 1989). There have been a number of interventional studies in which researchers attempted to use social support to augment education or to improve patient adherence. In two studies cited by Burroughs et al. from the 1980s, researchers found that a social learning intervention in which adolescents identified, and then role-played, social situations in which regimen adherence might be challenging showed better metabolic control four months later as compared to a non-intervention control group (1997). Another study ten years later, in which researchers looked at group problem solving combined with peer group support, also showed improved outcomes in adolescent diabetes patients, but this study lacked a control group (Løding, et al., 2007). In 2001, Greco et al. showed increases in social well-being for both diabetic teens and non-diabetic friends who joined them for a series of educational sessions (Cheung, et al., 2006). Interestingly, following an educational intervention for diabetic adolescents and one chosen friend, parents also reported decreased conflict (Greco, et al., 2001).

### Interactions with Providers

Interactions with providers are a theme that recurs in the literature, and a brief comparison is in order. Not surprisingly, the patient's experience is largely shaped by their interaction with their provider, and patients view being confirmed (i.e. listened to, treated as a person, and believed) as very important (Edwall, et al., 2008). In adolescents, "Providers who show interest in the adolescent as a person and pay attention to their life situations are giving the kind of support that increases compliance" (Dickinson & O'Reilly, 2004, p. 100). Despite the importance of provider interaction, there is evidence that family, friends, and spiritual practices have more impact on individuals' self management than providers (Handley, Pullon, & Gifford, 2010).

### Rural Issues

The rural setting provides unique challenges in diabetes management. In an Australian study comparing urban and rural adolescent diabetics, researchers found "significantly greater adverse impact in the rural group, particularly in self-esteem, parent emotional impact, family cohesion, and mental health measurements." (Goss, Paterson, & Renalson, 2009, p. 296). Issues include both physical obstacles provided by distance and psychological barriers created by rural culture.

The rural setting complicates delivery of both information and support in diabetes (Smith & Weinert, 2000). Travelling long distances to health care, provider turnover, and provider quality are problems for rural residents (Leipert, Matsui, Wagner, & Rieder, 2008; Winters, Cudney, Sullivan, & Thuesen, 2006). Jones et al. linked this difficulty to

social support, writing that rural African Americans have less access to health care and must rely more on family and friends for support (Jones, et al., 2008).

The psychological impact of the rural setting can be significant as well. Adolescents in rural areas are at increased risk for emotional distress compared to their suburban or urban counterparts, with suicide rates nearly 80% higher (Tusaie, et al., 2007). There is also increased use of alcohol and illegal drugs in rural areas (Leipert, et al., 2008). Of additional concern for adolescents with diabetes, being different may make one a more likely target of bullying, and bullying does occur in rural areas (Kulig, Hall, & Kalischuk, 2008).

Another potential barrier to providing care in rural areas is the social milieu. As explained by Smith and Weinert, “Rural residents are characterized by self-reliance and independence, rely heavily on an informal network of support, and may not be accepting of externally provided support” (Smith & Weinert, 2000, p. 646). This closed network may increase the need for peer or social support – when unwilling to seek help from outsiders, only insiders remain as potential resources. Interventions geared toward mobilizing support within the community, such as a rural diabetes education programs, have been shown to have positive effects on both knowledge and self efficacy (Bowman & Epp, 2005). Patients attending sessions had higher efficacy than non-attenders, despite similar knowledge, which the authors attributed to the positive interaction with peers and educators (Bowman & Epp, 2005).

Another area of concern is physical activity among rural residents. There is a relationship between activity levels and proximity to fitness facilities that results in lower

levels of physical activity among rural dwellers (Casey, et al., 2009). In one study of adults comparing urban and rural residents in New York state, researchers found that both physical activity and social support were lower among the rural residents – it was unknown if this difference reflected limited resources or the self-reliant culture of rural participants (Shaw, Gallant, Riley-Jacome, & Spokane, 2006). In another study of rural youth, investigators found both self-efficacy and social support to be related to physical activity levels, and combining the variables showed significant differences, indicating that the factors interact in complex ways (Shores, Moore, & Yin, 2010).

Technology has been put forward as a means to overcome the barriers provided by distance in rural areas. Some discussion of the impact of telephone and internet interventions is provided under the heading regarding Peer Support. More specific to this section, providing online support tools in rural areas was demonstrated to be feasible as early as 2000 (Smith & Weinert, 2000). In that study, participants responded positively to an online support intervention for adult women with chronic illnesses, with an astonishing 100% saying they would recommend it to others. More recently, 87% of adolescents reported using the internet, including 83% of rural respondents between the ages of 12 and 17 years according to the Pew Internet & American Life Project 2006 as cited in Krukowski et al. (Krukowski, Harvey-Berino, & West, 2010). Krukowski et al., discussing weight loss interventions, cited preliminary results among adults that suggest online interventions reduce stigma and improve efficacy for long term change (Krukowski, et al., 2010).

A more recent study of information sources for both rural and urban adolescents demonstrated similarities between both groups in their health concerns and how they seek information about those concerns (Larisey, Reber, & Paek, 2011). Larisey et al. found that adolescents demonstrated a high level of sophistication regarding online information sources, as well as “healthy skepticism” regarding the veracity of those sources (2011, p. 8). Once again, the potential of online resources was demonstrated.

#### Previous Uses of Pender’s Health Promotion Model

As previously discussed, Pender’s Health Promotion Model offers an advantage in understanding modification of behavior because it is based on the patient’s pursuit of improved well being rather than the avoidance of negative consequences. Timmerman’s investigation of how patients overcame the difficulty of implementing positive lifestyle changes found that 74.7% cited health promotion, while only 8.4% cited disease prevention. (Timmerman, 1999). Timmerman also found the use of social support to be effective (1999). As early as 1994, adolescents who defined health as the absence of illness were found to be less likely to engage in a health promoting lifestyle (Gillis, 1994). Social reinforcement, encouragement and peer involvement can all improve the implementation of health-promoting behavior (Ho, et al., 2010). In a study of 400 adult rural women using Pender’s framework, researchers found statistically significant relationships between social support and both health promotion and nutrition (Adams, Bowden, Humphrey, & McAdams, 2000).

The majority of work with adolescents using the HPM has centered around promoting physical activity (Garcia et al., 1995; Garcia, Pender, Antonakos, & Ronis, 1998; Powell-Young, 2009; Robbins, Gretebeck, Kazanis, & Pender, 2006; Robbins, Wu, Sikorskii, & Morley, 2008; Srof, 2006; Standiford Brown, 2009; Taymoori, Lubans, & Berry, 2010; Teerarungsikul, et al., 2009; Wu & Pender, 2002; Wu & Pender, 2005). This is an area of special interest to this research because physical inactivity is a risk factor for development of diabetes related complications, is a significant problem in most developed countries, and is affected by many interrelated factors, including social support (Cleland et al., 2010; Teerarungsikul, et al., 2009).

Investigators in the Girls on the Move study in Taiwan found that social support for physical activity increased among adolescent girls who participated in a computer and nurse practitioner based intervention (Robbins, et al., 2006). Further study conducted among Taiwanese adolescents led researchers to conclude that, while peer support did not directly impact physical activity, peer support did directly impact self-efficacy, which was found to be the strongest predictor of adherence to a physical activity program (Garcia, et al., 1995; Srof, 2006; Wu & Pender, 2002; Wu & Pender, 2005). Investigators conducting research here in the United States showed that students transitioning into middle school experience a significant decrease in both self-efficacy and social support for participating in physical activity (Garcia, et al., 1998; Srof, 2006). Investigators using a web based support intervention for adults in a rural area showed correlation between use of the support and increased physical activity. However, use and improvement both decreased over time (McKay, King, Eakin, Seeley, & Glasgow, 2001).

The unique demands of adolescent development make the applicability of interventions developed for adults limited – exploration of models that are appropriate to this age group is necessary to develop understanding of health promotion in this distinctive phase of life (Srof, 2006). A review of literature on improving physical activity and reducing obesity in adolescent girls included statements regarding how many early studies failed to account for the heavy influence of cognitive factors in this population's behavior and how those might be used to improve outcomes (Standiford Brown, 2009). The use of the HPM with this population helps to address these concerns in a variety of ways:

Pender developed her model from the health belief model and successfully addressed many of its criticisms. One especially important aspect of the health promotion model in terms of its usability with adolescents is that resources are addressed. Adolescents often have fewer resources than adults. Not only are financial resources significantly less, but adolescents also have less life experience and personal resources at their disposal. Additionally, because adolescence generally represents a period of health (as does childhood), adolescents often have fewer health and illness experiences. The health promotion model takes these issues into consideration to provide a usable framework for health promotion research with adolescents. (Montgomery, 2002, p. 132)

Other investigators have used the Health Promotion Model with adolescents to study spiritual growth, safety belt use, alcohol use, smoking behavior and food choices (Callaghan, 2005; Callaghan, 2006; Guthrie, et al., 1994; Riccio-Howe, 1991; Wang, Herting, & Tung, 2008). In all of these, support was found to be a major influence in the process of choosing health promoting behaviors.

### Gaps in the Literature

Lack of study specific to developmental stages and understanding the individual patient's viewpoint has been cited since the 1970s (Sullivan, 1979). Researchers have bemoaned the dearth of research on adolescent social support and related interventions for more than twenty years (La Greca, 1992; Lehmkuhl, et al., 2009). Others have complained about the lack of research into social support outside family and the patient's perspective (Skinner & Hampson, 1998; Vandam, et al., 2005).

This literature review has clearly demonstrated that there are inconsistencies and contradictions in the existing research. This is at least partially due to incompletely developed methods. An attempt to assess health promoting behaviors of rural adolescents in 2000 was hampered by assessment tools worded for adults that adolescents found difficult to relate to (Hendricks, et al., 2000). Some of the inconclusive results may be attributable to inconsistencies in population studied. For example, one study starts off being described as about "adolescents," but the 231 patients sampled were ages 18-25 (Berlin, et al., 2002). This researcher would argue that many of these studies attempted to understand the effect of an adolescent's world on their actions without first fully understanding their perceptions of their world.

Finally, out of 159 unique sources, social networking online (e.g. Facebook) was only addressed once, and that was in a study of seventh graders (Larisey, et al., 2011). As Facebook policy requires profile holders to be at least fourteen years old, seventh graders may not be the ideal group to investigate use of this resource. Investigations of online support and interventions have otherwise used purpose-built or thematically

focused websites and resources, but little investigation of how these patients use existing or more generalized options has been done.

## CHAPTER THREE: METHODS

The purpose of this study was to investigate how adolescent diabetics experience social support from friends and peers in relation to their diabetes. This chapter will present the methodology for this investigation by presenting the design, population and sample, setting, procedures for data collection, human subject considerations, and analysis methods.

Design

This study will use a phenomenological approach to describe the lived experience of peer social support by adolescent diabetics. The question of how these participants experience social support from their peers lends itself to this type of approach because phenomenology is especially appropriate for problems in which “it is important to understand several individuals’ common or shared experiences of a phenomenon” (Creswell, 2006, p. 60).

This study design becomes relevant to Pender’s Health Promotion Model (HPM) as an underpinning for intervention (Pender, Murdaugh & Parsons, 2011). Effective educational interventions for health promoting behaviors seem to be those that are highly targeted to individual experiences (Dalum et al., 2008; Hanna & Decker, 2010; Langlois et al., 1999; Schlundt et al., 1996). Pender, Murdaugh, and Parsons describe the need to further define interventions to enhance social support as one aspect of health promotion (2011). It is this researcher’s assumption, based on the combination of these factors, that

understanding the common experience of these adolescents is a necessary precursor to designing and implementing interventions that specifically address that experience.

### Population and Sample

A combination of convenience and snowball sampling was used to recruit participants for the study. The study sample consisted of adolescents aged 12 to 18 years (inclusive) diagnosed with Type 1 or Type 2 diabetes without regard to length of time since diagnosis. Participants who met the inclusion criteria based on age and diagnosis who could speak English were eligible.

### Sampling

Written materials were provided to participating clinics that included an overview of the study design (Appendix B), a consent form and researcher contact information. Clinic staff members were asked to provide this information to any eligible adolescent the staff perceived as receptive to participating in the study. Persons indicating interest in participating were offered the option of either contacting the researcher to schedule an interview or signing a consent for the researcher to contact them. At conclusion of the interview, participants were asked whether they knew anyone else who might be eligible and interested in participating. If so, a copy of the previously described written packet was provided to the participant to share.

Interviews were conducted toward the goal of achieving saturation which, in this case, refers to a state in which ongoing sampling ceases to reveal new data (Munhall, 2007).

### Setting

Participants were recruited from area clinics in south central Montana. Three (3) clinics from a city in the region, whose patient population includes adolescents with diabetes, agreed to provide recruitment materials to patients during visits. Interviews were then conducted around the city at mutually agreed upon locations.

### Procedures for Data Collection

The opening step of this study was be a self-reflective period of approximately one month during which this researcher sought to define and set aside this researcher's own experiences and assumptions regarding diabetes and social support. This *epoche*, or bracketing, exercise is a necessary precursor to phenomenological research that allows the researcher to differentiate his or her own experiences from those of the study's participants (Creswell, 2006). Literature review was conducted following the epoche period.

One-on-one interviews were conducted with this researcher and audio recorded. Because adolescents consider confidentiality and privacy of immense importance, parents were included only in the initial explanation of the study and confidentiality in order to facilitate honest, uninterrupted responses by adolescents (Carlisle, Shickle, Cork & McDonagh, 2006). Specifics of the interview questions will be addressed under the heading "Instrumentation."

These interviews were designed to last approximately one half hour to minimize inconvenience to study participants and their parents or other adult caregivers.

Scheduling was, however, flexible to allow participants to provide more time if they so desired. Ideally, phenomenology involves a series of lengthy interviews – Marshall and Rossman cite a standard of three (2006). This process was compressed here to a single interview per participant due to the time constraints imposed by the thesis schedule.

### Instrumentation

Interviews were conducted using open ended questions in one-on-one interviews between this researcher and adolescent participants. Phenomenological interviews are often highly conversational in structure, so development of interview questions for this study was deliberately kept to a minimum to allow maximum freedom of exploration and response by the participants (Munhall, 2007). Interviews were conducted according to the model in Figure 2 and participants were allowed to answer freely. This interviewer used phrases such as “could you give me an example of that?” “Do you remember how that made you feel?” and “how was that?” to draw out details from initial responses (Munhall, 2007, p. 185).

### Human Subjects Considerations

#### Rights and Consent

This study in was approved by the Montana State University Institutional Review Board (IRB) and the Billings IRB Executive Committee. Permission was also obtained from the managers of the clinics where data collection occurred.

The sampling structure of this study was designed to help protect participant privacy rights by making all consent for contact initiate from the participant to the researcher. This researcher at no time “cold called” new potential participants, and no participant was contacted after the conclusion of their interview by the researcher.

Consent forms were provided to all participants and their parents or guardians, along with verbal explanation of the study, their rights, and opportunity to have any procedural questions answered. An example of the consent form is included in Appendix A and the HIPPA disclosure used is available as Appendix C.

### Disclosures

All adolescents who agreed to participate in this study were provided with an incentive in the form of a \$10 iTunes gift card after they signed the consent form. This incentive was provided regardless of the length of interview the participant provided or whether the participant chose to withdraw from the study. Participants received verbal explanation that accepting the incentive gift card did not place them under any additional obligation.

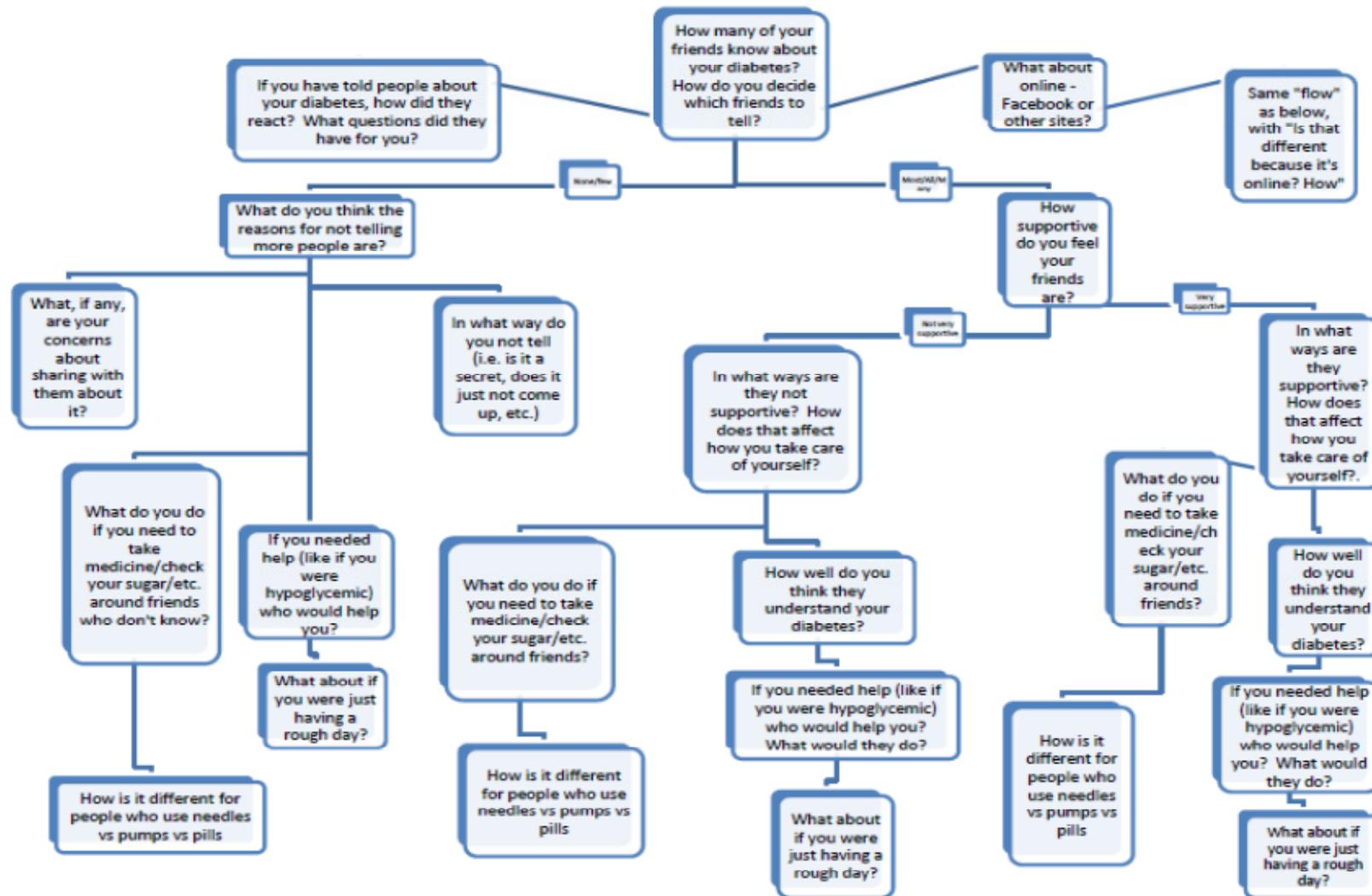
### Analysis Procedures

Following the conclusion of interviews, recordings were rendered into verbatim transcripts by this researcher. These renderings were verified for accuracy by the researcher’s thesis committee chairperson. These renderings were then reviewed for specific statements that provide insight into the participants’ experience, and these

statements further clustered between interviews into themes as trends began to emerge (Creswell, 2006).

Themes were identified and refined using an inductive approach – rather than coding and counting predetermined themes, transcripts were mined for explanatory language that spoke to participants’ experiences (Norwood, 2000). This approach was designed to preserve as much as possible the richness of responses and provide the most complete achievable picture of the experience (Norwood, 2000). This researcher then used these themes to develop statements summarizing the “essence” of the participants’ experience (Creswell, 2006, p. 62).

Figure 2: Interview flowsheet



## CHAPTER FOUR: RESULTS

Sample Demographics

Participants were recruited and interviewed during an eight week period January-March 2012. Five (5) participants completed interviews during this period. Table 1 lays out participant demographics.

Table 1: Participants in interview sample (N=5)

Participant	Age	Gender	DM Type	Age at Diagnosis	Insulin delivery
A	16	Female	1	10	Pump
B	17	Female	1	11	Pump
C	12	Female	1	11	Pump
D	13	Female	1	9	Pump
E	18	Female	1	5	Pump

Themes Identified

Analysis of interviews revealed nine themes. These are summarized in Table 2.

Table 2: Themes Identified and Defined

Theme Title	Definition
Full Disclosure	Participants did not express any need to conceal their diabetes from social contacts.
Taking Care of Myself	Participants described maintaining their well being as a priority.
Getting Help	Participants perceive social contacts as helpful with diabetes care and safety, although the form that help takes varies.
Making It a Part of Life	Participants prioritize incorporating diabetes into their daily lives with as little disruption as possible.
People Who Know Are Important	Participants describe friendships with diabetic peers as different from other relationships and as important.

Table 2 Continued

Sharing Information as Positive	Teaching and mentoring were viewed as positive by participants.
Adults as Negative Reactors	Participants tended to describe more negative reactions from adults than from same age peers.
Age Differences Make a Difference	Concerns and levels of connection with peers varied with age and number of years diagnosed.
Heavy Issues Early in Life	Some participants describe facing emotional challenges related to their diabetes at young ages.

### Full Disclosure

Nearly all the participants stated that “all” of their friends were aware of their diabetes. Participant C, a twelve year old female, stated “most” friends knew. Most participants described disclosure as occurring because new acquaintances inquire about equipment or care behaviors. As participant A stated, “...they actually usually ask me first cuz they saw my pump when they first met me and asked about it, so I told them, ‘yeah, I’m diabetic.’” Participant D described her disclosure process as casual, stating, “if it comes up it comes up... it’s not really a big deal that they know.” Participant B actually described her disclosure as an active decision related to safety, which will be discussed under the theme *Getting a Little Help*.

Participant A also felt that openness about having diabetes was the most common response. She stated regarding her experience with other diabetic teens at diabetes camp, “I think they all are pretty open about it.” The three oldest participants, who had all been diagnosed with diabetes for at least 6 years, mentioned feeling as though they’d had the condition “all my life,” as A put it. It was an integrated part of their identity.

Participant D had recently experienced a hospital stay for diabetic ketoacidosis. She discussed the process of reporting this event to her friends by saying, “I didn’t tell anyone until school ‘cuz I didn’t wanna explain over texting or calling – just ‘cuz it’s a little crazy to explain and didn’t wanna freak anyone out. So, I wanted to be better when I explained so I didn’t scare anyone, so I didn’t tell ‘em until school, but they all know now.”

### Taking Care of Myself

All the participants stated that they would still follow their care routines if they experienced social challenges in the form of friends who were unreceptive to using needles or pumps. Responses ranged from stating they would be unlikely to continue the friendship, as participant A stated “...who are you.. to judge me just cuz I have a disease...” and, later, “if I went blind or had to lose a leg cuz of diabetes I don’t think I could handle that, I’d rather take care of that now than, like, trying to impress these ‘friends,’” to accommodating the friend by doing blood tests and injections in another room or restroom. Participant D reported that her best friend is actually quite uncomfortable with blood . D stated that she handles this by warning her friend when she tests, at which point the friend turns away, but this is not a disruption to her care behaviors. None of the participants felt friends had a direct impact on self care behaviors (except as discussed in *Making It A Part of Life*), and reported diabetes related stress as more related to health than social concerns.

### Getting Help

When asked whether their friends understood diabetes well enough to react appropriately to a hypoglycemic episode, responses were divided. There were three participants, A, B, and D, who stated that their friends were aware what to do during a hypoglycemic episode and had done so in the past. When discussing her level of openness about her diabetes, participant B stated, “I’m just gonna tell someone because I know that’s safest for me, cuz if something went wrong with me, like medically wrong, they would need to know how to deal with it. Like, it’s just safest if people know.”

Interestingly, B was the only participant who reported a major incident involving personal safety and diabetes. She had experienced a pump malfunction that led to her being unable to safely finish driving a friend home because her blood glucose level was above 500 – the friend had to cope with the situation and get B home, largely unaided. They were able to manage the situation without permanent impact on either health or friendship, but it left an impression with B.

Participant C was less clear on her friends’ response, saying that “some of my friends [would] probably freak out and some would probably remember [what to do].” Participant E also showed a low level of confidence in most of her friends – she felt family members knew how to handle hypoglycemic episodes but friends would likely not know what to do other than “call 911.”

None of the participants had experienced a great deal of interference in dietary choices or care behaviors from friends. For participants A, B and C, friends were not perceived as likely to remind participants to test blood glucose. Participant A states,

“They’re not like so in tune about it, they forget about it.” For D and E, however, friends do provide this type of practical support from time to time from certain friends. Both participants both found helpful and denied any annoyance at being reminded to test their blood sugar.

### Making It a Part of Life

All participants except E were transitioned from injections to insulin pumps within one year of diagnosis, and all five participants made statements that they preferred the pump. Participants A, C, and D, described testing blood sugar and using their pumps to bolus in public, but stated they would go somewhere more private to use a pen or needle if they had to. All participants denied ever actively deciding to skip a bolus for social reasons, but A and B admitted to occasionally forgetting when busy with friends. Participant A said, “[if] I would ever skip a bolus it would definitely have to be when you’re out with your friends, you know, out at a restaurant or enjoying a movie, out on the town or something like that, where you’re just so busy you just kinda forget.” Participant B has a similar description about checking her blood sugar levels, feeling that “just this once” can turn into a whole day when busy with friends. D and E denied having trouble fitting in care behaviors.

Some participants felt that healthcare providers needed to understand the realities of dealing with diabetes and trying to live a normal life. Participant A, when asked what healthcare providers should know about living with diabetes, stated “I feel like doctors and all that need to know we’re human too and we’re not perfect so if sometimes if you’re slacking like if you don’t ... test exactly every two hours it has to be ok because

life doesn't allow you to be perfect all the time." Participant B, when asked the same thing, wanted providers to have practical expectations, for example "because [the provider] always wants me to do one [test] from like night to morning, like 10 in the morning, so that means I have to get up after not eating all night, not eat in the morning and go to school" which she felt was not practical. D also expressed frustration with healthcare providers, saying, "...we're still teenagers... just because we forget to test we forget to test... we can't be business all the time."

All participants except E described their level of social freedom as equivalent to same age peers. They participate in overnight social events, jobs and school activities without perceiving their diabetes as a limitation. Participant A mentioned that her freedom to, for example, stay overnight at a relative's home was severely curtailed the first year after diagnosis, but she feels that she is now on par with her same age peers again. B describes herself as being free to participate in activities as long as she updates her parents frequently. C repeatedly mentioned texting her parents on her cell phone to double check carb counts and report testing results, but felt this was the only difference in her social freedom. E described severely curtailed social freedom as a younger child and teen, but also mentioned that this was "my fault" because she was unable or unwilling to assume the responsibility for drawing up her own insulin.

#### People Who Know Are Important

Participant A, B, and D stated they have diabetic friends from other areas of the state whom they met at camp. None of the participants spend time with other local diabetic teens socially, even those who knew of others in their schools. Participant A

stated “I’m like only one of two in my school that has diabetes and I don’t even know the other kid that has diabetes so I’m pretty much just alone with it.” They stay in touch primarily using phone calls (1 participant) and Facebook (2 participants). Participant D stated she is “really bad at keeping contact” with her friends for camp, but she is also too young to have a Facebook account.

All participants stated that they do not discuss their diabetes with non-diabetic friends – issues of frustration with the condition or difficulties with healthcare providers do not come up. This is stated to be partially because it simply isn’t a major issue and partially because friends wouldn’t understand these issues. They do, however, discuss these issues with other diabetics. Participant A explained, “...we’ll talk about diabetes sometimes we’ll compare lows and do all this stuff that I don’t talk about ... with my friends that don’t have it...” Patient C did not have any friendships with other diabetics, but does have an older cousin who also has type 1. She stated that her cousin would help her with care behaviors, like counting carbs, but was unsure who she would discuss concerns about her diabetes with. Participant D, who knows other diabetics but does not speak to them regularly, stated “I don’t really have anyone that I really talk to about it – I just kind of keep it in, work through it.” D also emphasized the importance of peers at camp, pointing out repeatedly how important it was to see other people who went through the same things on a daily basis.

Participant E, who has never been to diabetes camp, does not have any friends with diabetes but reports her cousin is understanding about diabetes related issues because of other diabetic family members. Her aunt, who is diabetic also, is a major

influence on her behavior. She reports her decision to adopt the insulin pump was almost entirely because her aunt had one and liked it. She also expressed interest in networking on social media with other diabetics, although she has not done so at this point.

Participant A was the only one who had heard from diabetic peers about bullying that was associated with or affected diabetes care. One of her acquaintances at camp had reported some bullying behaviors that manifested as intentional pulling of pump infusion lines – A reported being startled and frightened by this report, but also considered it unusual.

#### Sharing Information as Positive

All participants described their non-diabetic friends as having some understanding of diabetes, perhaps more than the average person. They also felt that their non-diabetic friends' knowledge was at a very basic level. Low blood glucose or odd behavior is responded to by offers of soda or snacks by knowledgeable friends, but also often by an inquiry as to what the participant wants them to do rather than independent action. Participant C also cited some confusion among classmates as to the difference between type 1 and 2. None of the participants expressed annoyance at answering questions or explaining their care behaviors in social situations.

When asked if they would like an opportunity to increase friends' knowledge, such as at a diabetic education class designed for them to bring a friend, all participants responded favorably. Participant A responded to the idea of such a class by saying, "Now that would be helpful, cuz then they would, like, they could learn more about diabetes and what it is and stuff." B, who (as described previously) has actually

experienced needing assistance from a friend stated that improved understanding would be useful because “they would understand it and know how to help me more than, like, ‘are you ok, what do you want me to do’ – instead of asking they [would be] just like ‘ok, I’ll do it.’” B was also the only participant who reported carrying and having friends trained to use glucagon.

All three older respondents also responded favorably to inquiries about mentoring. Participant B actively participates in a mentoring program at diabetes camp, in which older campers are trained to become counselors. She describes enjoying working with much younger diabetic girls (as young as age 8) and helping them understand how to care themselves as being a very positive experience. Her last time at camp, she also experienced an incident she found frightening – another camper had a severe hypoglycemic episode resulting in a seizure. This incident was not related to the younger campers in her care, however, out of a desire to avoid frightening them. She also described her own care as being improved by her desire to be a good example.

Participant E has been approached by her healthcare provider about a potential mentoring program for young diabetics in the area, and expressed considerable excitement about the prospect. When asked if there was anything good about her diabetes, she said, “...a lot of the times, most of the time, I feel like I’m almost blessed with it, that I was picked to deal with this, and I can help other people, I can inform people what it is...”

### Adults as Negative Reactors

None of the participants described friends as interfering with food choices. Friends' parents, however, were mentioned as having misconceptions about what foods can be eaten and providing troublesome interference by 4 of the 5 participants. Participant A feels that some parents have a misunderstanding, likely dating from older treatment regimens, that diabetes means no sugar can ever be consumed. Participant B dislikes testing her blood glucose in public places because she feels adult strangers have a tendency to stare. Participant E had significant negative interference from adults, which is discussed under the section *Heavy Issues Early in Life*.

Participant B related a story "In 6<sup>th</sup> grade, I still had... my pump was still kinda new, so I was using this huge hip clip, and it was kinda sticking out for picture day, and the picture lady's like, 'you need to take off your cell phone.' [I said] 'uh, it's not my phone.' I'm all like 12 years old... 'well, you just need to, that can't be in your picture' and she's like nagging me about taking it off! ... Eventually I kinda like lifted up my shirt, 'cuz my site was on my stomach, I was like, 'look this is my medicine I can't take this off' [and she said] 'ok, I'm sorry.'" B also experienced one teacher who was critical of the school's policy that required a classmate to accompany B when going to the office for help with a hypoglycemic episode – although B viewed this as an isolated incident.

Participant C discussed the most interaction with adults regarding her diabetes, as she is younger and more newly diagnosed and therefore requires more assistance with management. She initially denied being bothered by this increased interference from

parents, nurses and teachers, but at later in the interview did express some mild frustration with the constant presence of the school nurses.

### Age Differences Make a Difference

Participant A felt living with diabetes becomes less comfortable as age increases because of the increasing complexity of one's social life. Participant B, however, describes the young girls at camp as being very dependent. Speaking of helping them count carbohydrates at meals, she said, "...they wanted me to do it a lot, like here, do this for me... [I would say] okay, you have to figure it out because I know that you can learn to do it yourself." Participant C's reports of her self care repeatedly involved references to adult assistance – her parents or school nurses almost always assist her in calculating carbohydrate based insulin doses, which is consistent with B's experience of younger campers. C also differed from older respondents in that her complaint regarding healthcare providers was not regarding understanding about integrating diabetes into daily life but rather about physical discomfort associated with injections – "I think they should sometimes feel shots because they hurt." C was also more focused than the older participants on food choices. She twice brought up friends' eating behaviors, stating that when out with friends they would often indulge in sweet snacks she felt she should abstain from. Although she did not feel as though they needed to change their choices to improve her comfort, her repeated discussion of this issue did carry a tone of mild frustration.

### Heavy Issues Early in Life

Participant D has been competing in swimming for several years, including prior to her diagnosis. She described the first few months after her diagnosis as creating difficulty in this area of her life because she was repeatedly questioned regarding “are you sure you want to keep swimming.” She also mentioned that other swimmers had negative perceptions, stating they had an attitude of “...really, I’m racing that diabetic girl? I feel bad for her, like she’s gonna get beaten really bad.” She stated that she had to prove herself at the age of 9 to put an end to the questioning.

More significant was participant E’s reported experience. When E was 10 years old, in the fifth grade, she was still dependent on adult assistance to draw up and administer insulin using needles. Her school did not have a school nurse on staff, so her mother came to school every day to help her inject her insulin. The principal and her fifth grade teacher did not approve of her mother’s presence on campus and informed the family that this would no longer be permitted – E would be required to administer her own insulin. E did not feel ready to assume this responsibility, so the decision was made to homeschool her, which is how she completed the remainder of her schooling. She also reported being failed by a PE teacher because of taking breaks to test her blood sugar.

## CHAPTER FIVE: DISCUSSION

This study sought to increase understanding of how adolescents with diabetes experience friend and peer support. Based on Pender's Health Promotion Model, this was intended to serve as a first step toward improving understanding of the variables underlying teen behavior so that more effective interventions may eventually be crafted. Themes identified were: full disclosure, taking care of myself, getting help, making it a part of life, people who know are important, sharing information as positive, adults as negative reactors, age differences make a difference and heavy issues early in life.

### Findings

#### Technology

One finding that stands out is the impact of technology on several of these themes. Under the theme making it a part of life, participant's responses indicated that they were more willing to use the pump in social situations than pen or needle delivery systems. In keeping with literature findings indicating that care activities interfere with social activities by taking time, this willingness may reduce the impact care behaviors have on social functioning (Lehmkuhl, et al., 2009).

The participants' willingness to use their pumps in public but not other insulin delivery devices may also speak to decreases in their perception of negative reactions. None of them indicated feeling fearful about others' reactions to their diabetes care behaviors when using their pumps. This is in contrast to some previous studies, and may demonstrate a positive impact on social functioning related to the newer delivery devices.

This also provides an interesting contrast to concerns raised in the literature about the emphasis on intense management – these technological advances may be improving psychosocial functioning as a beneficial side effect (Skinner, et al., 1999).

Finally, two of the older participants were enthusiastic about social networking, specifically the website Facebook, as a means to access peer support. They confirmed literature findings that peer support from other diabetic adolescents provided unique forms of support which they found to be important (Hughes, et al., 2009; Kyngas, 2004; Sumner, et al., 2001). While none of the participants in this study live in a rural area themselves, the social networking findings are still of interest for the rural setting because of the distances these participants described overcoming. None of the participants cited having social connections with other local diabetics, forcing them to find other ways to access peer support. Among those who did report keeping in touch with peers, the friends whom they used for peer support lived hundreds of miles away, making the internet an important tool to access this support.

### Peer Relationships

Peer relationships were important to those who had experienced them. Also, those who kept closer ties with peers (such as friends from camp) described less isolation and more ability to receive support specific to their diabetes. Peer mentoring also came up as an area of interest – B had experience providing it, which she viewed as positive for both herself and those she mentored, and A expressed interest in assuming a mentoring role. Hughes' findings of possible negative impacts were not borne out in B's experience

– because she had guidance as to appropriate mentoring decisions, she was able to tailor her guidance to the younger campers to help them without frightening them (2009)

As discussed above, peer relationships were discussed as being different from relationships with non-diabetic friends, and both types of friendships were considered important by those who had experienced both. This confirms the trend in the literature – that peers generally provide positive support (Cudney, et al., 2005; Hughes, et al., 2009; Sumner, et al., 2001). Also consistent with the literature was the youngest participant’s reliance more on parents than peers (Bokhorst, et al., 2010; Leonard, et al., 2005).

### Impact of Adults

Interestingly, these participants’ responses would seem to indicate more difficulties with adults than with same age peers and social contacts. Reports of hassling about dietary choices, “staring” in public, and misunderstandings about the importance of complying with safe care practices all came from adults. Also, none of the participants reported having providers inquire about their social functioning, which was cited in the literature as being one way providers could improve adherence (Dickinson & O’Reilly, 2004; Spencer, 2011).

The parents of many of these teens did appear to be helpful in the handling of the balance between diabetes and social needs. All but one self-assessed their level of freedom as equal to their peers. They reported being able to participate in outings, including overnight, away from parents without burdensome interference. This is in keeping with literature findings that indicate finding ways to integrate normal social activities is a vital teaching point for parents (Betschart, 1999).

### Study Limitations

This study's limitations are primarily related to its small sample size and the method by which that sample was recruited. A sample of 5 adolescents cannot provide the breadth of experience necessary to comment on the general experience of this population. Also, in asking for volunteers for in-person interviews, an element of sampling bias was introduced. Participation was by those comfortable with meeting a researcher and answering questions. Adolescents who are less comfortable with their diabetes, and therefore more likely to conceal it or have negative experiences to report, would be unlikely to respond.

### Implications

#### Research

It is clear that the existing understandings of how the adolescents' social milieu interacts with his or her diabetes care are, at best, inconsistent. In light of the clear importance of this phase of life with regards to developing lasting behavioral patterns, further investigation is warranted. Given the findings here regarding the impact of technology in lessening the sense of difference felt by teen diabetes patients, a larger investigation of how technological advances are viewed and utilized might uncover both more detail regarding how social support works in the age of Facebook and further strategies for the clinician.

### Education

All five participants expressed interest in education sessions that included non-diabetic friends. All five showed interest in either providing or receiving mentoring from peers. The literature upholds the effectiveness of group classes. It is clear that designing educational practices that provide this type of opportunity has enormous potential. In the rural setting, this may be another area where technology comes to the fore. Long distances may preclude some interested teens from participating in person, but previous investigations of distance mentoring and support have had positive results.

### Practice

The major implication from the responses of these participants is that clinicians must demonstrate some awareness of the inconvenience of incorporating diabetes into daily life. This is in keeping with literature findings that patients prefer to be worked with rather than lectured at. While finding the time to discuss a patient's social life in a short office visit may seem like a distraction, these participants clearly appreciated acknowledgment that their condition was one aspect of their life and not by any means the only aspect.

### Conclusion

The results of this study confirm that adolescents with diabetes find social interaction to be of great importance in their daily lives. It did not uphold negative impacts from social interaction on care behaviors, except in the sense that busy or exciting activities may lead to reduced compliance due to forgetfulness. It upheld the

idea that balance between diabetes care and the rest of life is paramount to an adolescent's quality of life. It also emphasized the impact technology, such as insulin pump use and the internet, has had on the structure of life for teens with diabetes.

Understanding the context in which these teens live is vital to crafting successful interventions. That context includes family, friends, teachers, peers, and technology. Researchers and clinicians must strive to account for this context when investigating or working with this population if either research results or interventions are to have meaning.

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APPENDICES

APPENDIX A

SUBJECT CONSENT FORM FOR PARTICIPATION IN  
HUMAN RESEARCH AT MONTANA STATE UNIVERSITY

SUBJECT CONSENT FORM FOR PARTICIPATION IN HUMAN RESEARCH  
AT MONTANA STATE UNIVERSITY

**Title:** The Lived Experience of Social Support in Adolescent Diabetes Patients

Billings IRB Protocol No. 12.05

You are being asked to allow your adolescent child to participate in a research study. The purpose of this consent form is to give you information you will need to help you decide whether or not to enroll your adolescent child in the study. Please read the consent form very carefully. You are encouraged to ask questions about the purpose of the research, the possible risks and benefits, your rights as a parent, the rights of a participant, and anything else about the research or this consent form that is not clear. This process is called 'informed consent.' For anyone under 18 years of age, the consent of parent(s) is required. The assent of a minor who is older than six years of age is also requested prior to participation in a research study. You will receive a copy of this form for your records.

You/your child are being asked to participate in a study of friend support for people ages of 12 to 18 with diabetes. Up to 25 adolescents will take part in this study. The study is being conducted by Daen Scott, RN, a Family Nurse Practitioner student from Montana State University College of Nursing.

You were identified to receive information about this study by someone at a clinic or someone you know who has already participated in the study. Ms. Scott, the nurse practitioner student, did *not* receive personal information about you/your child.

If you/your child agree to participate, you/your child will be interviewed by Ms. Scott, the family nurse practitioner student. Parents or legal guardians will be asked to be present to discuss the consent and have any questions answered. However, the interview itself will be conducted with only the family nurse practitioner student and the adolescent present in the interview room. Interviews will last a minimum of 30 minutes. They may last longer only if everyone involved agrees to a longer interview session. Interview questions will be about your child's relationship with friends and whether or not those relationships affect your child's perception and management of his or her diabetes.

This study involves no treatment or experimental procedures. There are no significant risks to you/your child from participating in this study. If you/your child feel uncomfortable sharing his/her thoughts about the support they receive from their friends, you/your child are free at any time to decline to participate or free to withdraw at any time from participation in the interview.

If you choose not to participate, or withdraw from the study, this decision will in no way influence your health care.

This project receives no outside funding, and there is no charge for you/your child to participate.

Adolescent interview participants will receive a \$10 iTunes gift card when they agree to participate in the study. Receiving this card does not obligate you/your child in any way, and he or she may choose to leave the interview at any time.

Your identity and your/ your child's participation in the interview will be kept strictly confidential (secret). Your names will appear only on this consent form, which shares a coded identifier number with the interview records solely for the purpose of removing interviews from the study, should you/your child request that the interview record be removed. Interviews will be audio-recorded, and the recordings will be used to make written transcripts. These recordings will be listened to only by Ms. Scott, the family nurse practitioner student, and by a member of her thesis committee for the transcription process, after which the recordings will be destroyed. No names will appear on the written transcripts, and no names or identifying information will be included in the final study report. This consent form will be kept on file by Montana State University for 5 years, after which it will also be destroyed.

The only medical information Ms. Scott, the Nurse Practitioner student, will have access to is the diagnosis of diabetes for the purpose of deciding eligibility for the study. Should any further medical or other personal information be provided during the interview, this information will be kept confidential as described above. At no time will Ms. Scott access the participant's medical records for this study.

Further, any information shared during this interview will be kept confidential unless otherwise required by law (such as if the participant shares suicidal or homicidal intent or any mention of abuse is made). If the participant shares that he or she is not following his or her care regimen (e.g. he or she is skipping insulin doses), Ms. Scott will advise him or her to discuss this with a primary care provider but will not personally share that information with either other healthcare professionals or the parent or guardian.

Every effort will be made to maintain confidentiality of your personal information. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. If information from this study is published or is presented at a professional meeting, subject name or other personal information will not be used. Organizations that may inspect and/or copy research records for quality assurance and data analysis include St. Vincent Healthcare, Billings Clinic, the Children's Clinic, and the Institutional Review Boards of Billings and Montana State University.

In the event your/your child's participation in this research directly results in injury or discomfort to you or your child, you will be encouraged to contact your personal health care provider. Should you/your child have further questions, you can contact Ms. Daen Scott, RN at [daen.scott@msu.montana.edu](mailto:daen.scott@msu.montana.edu) or 406-534-9062 or her thesis advisor, Dr. Charlene Winters at [winters@montana.edu](mailto:winters@montana.edu) or 406-243-4608. If you/your child have additional questions about the rights of human subjects, please feel free to contact the Chair of the Institutional Review Board at Montana State University, Dr. Mark Quinn,

(406) 994-4707 [mquinn@montana.edu]. In addition, for questions about your rights as a research participant, you may contact the Institutional Review Board (IRB) of Billings, which is a volunteer group that acts as a research subject advocate. The IRB has reviewed this consent form for clarity of information. If you have any questions, comments, or concerns about this study or about your rights as a research subject, you may call the IRB of Billings at (406) 238-5657.

**INFORMED CONSENT - PARENT/GUARDIAN**

PARENT/GUARDIAN CONSENT: I have read the above and understand the discomforts, inconveniences and risks of this study. I,

\_\_\_\_\_, (*name of parent or guardian*),

related to the subject as \_\_\_\_\_ (*relationship*),

agree to the participation of \_\_\_\_\_ (*name of subject*) in this research. I understand that the subject or I may later refuse participation in this research and that the subject, through his/her own action or mine, may withdraw from the research at any time between today's date and March 15<sup>th</sup>, 2012. By signing this form, I have not given up any of my child's legal rights as a research participant. I have received a copy of this consent form for my own records.

MINOR ASSENT: I have read the above with my parent or guardian and understand the discomforts, inconvenience and risk of this study and have received answers to my questions about this study. I, \_\_\_\_\_ (*name of subject*), agree to participate in this research. I understand that I may later refuse to participate, and that I may withdraw from the study at any time between today and March 15<sup>th</sup>, 2012. By signing this form, I have not given up any of my legal rights as a research participant. I have received a copy of this consent form for my own records.

Signed: \_\_\_\_\_

Date: \_\_\_\_\_ .

PRINCIPAL INVESTIGATOR SIGNATURE: I have explained the study and the consent process and have witnessed the consent and assent signatures.

Signed: \_\_\_\_\_

Investigator Name: Daen Scott, RN

Date: \_\_\_\_\_ .

APPENDIX B

RECRUITMENT FLYER

What is it really like?

What: A study about having friends and having diabetes – what is it really like?

Who: Any person between the ages of 12 and 18 who has been diagnosed with diabetes.

When: At a time that's good for you, scheduled using the contact info below.

Why: This study will be used to complete the graduate nursing student's master's thesis.

How: An interview. If you're interested (and your parents say it's ok), you and your parent will meet with the graduate nursing student and get more information about the study. You'll both sign a consent form (a copy is attached for you to look over, but please wait to sign it) and then you'll talk with the graduate nursing student by yourself for about one half hour or longer if you want.

Everyone who participates gets a \$10 iTunes gift card.

If you think you might be willing to participate, please call or email:

Daen Scott, RN

Family Nurse Practitioner (FNP) Student  
Montana State University College of Nursing

[daen.scott@msu.montana.edu](mailto:daen.scott@msu.montana.edu)

406-xxx-xxxx

You may call or email with any questions you may have.

You are not obligated to participate in the study, and you can change your mind at any time.

All interviews and names of participants will be kept strictly confidential.

APPENDIX C

HIPAA AUTHORIZATION FORM

## Addendum to Consent Form: Privacy Authorization

## Protocol 12.05: The Lived Experience of Social Support in Adolescent Diabetes Patients

## Explanation and Background

Records – Use and Disclosure This attachment to the information and consent form provides additional information about how your medical records and health information (together, your “records”) will be used and disclosed for this study. Your records may include information about any data collected or reviewed during the course of the study as described in the consent form.

This form allows the study investigator identified in the consent to use your records to carry out the study described in the consent form. By signing this form you allow the study investigator to disclose your records to the sponsors identified in the consent. The sponsor may use the information to review the results of the study. The data sent by the study investigator to the sponsor usually does not include your name, address, or social security number. However, the sponsor might review or copy all of your records to assure the quality of the study or for other uses allowed by law.

All of your records, the signed consent form(s), and this form also might be reviewed or copied by St. Vincent Healthcare, the Children’s Clinic, Billings Clinic, or by the Institutional Review Board (IRB) of Billings, or by other regulatory agencies in this country. These agencies might review your records to check the information collected in this study, to check how the study was conducted or for other uses allowed by law.

Possibility for Re-Disclosure Federal and state laws require the study investigator to protect the privacy of your records; however, absolute confidentiality cannot be guaranteed because of the need to disclose information as described above. In addition, after the study investigator discloses your records to others, then the law may no longer protect the privacy of the information. If you would like to know how the sponsor will protect the privacy of your records, ask your study investigator how to obtain this information. If you would like to know how the IRB will protect the privacy of your records, you can contact the IRB at the telephone number listed in the consent form.

Temporary Lack of Access to Research Records By signing this form, you agree that you might not be able to review some of your records related to the study until after the study has been completed, at which time your right of access will be restored.

Participant’s Initials \_\_\_\_\_ Date \_\_\_\_\_

Consent Addendum: Privacy Authorization, Page 2

Authorization Requirement for Participation If you do not sign this authorization, you cannot participate in the study. You can cancel this authorization at any time by giving a written notice to the study investigator. If you cancel this authorization, then you no longer will be able to participate in the study. If you cancel this authorization, then the study investigator will no longer use or disclose your records unless the study investigator needs to do so in order to preserve the scientific integrity of the study. The investigator may still use the information that has already been collected.

Duration of Authorization This authorization does not have an expiration date. If you do not cancel this authorization, then it will remain in effect indefinitely.

Privacy Authorization

I authorize the release of my medical records and health information related to this study, including my signed consent form and this addendum, to the sponsor and its representatives, St. Vincent Healthcare, the Children’s Clinic, Billings Clinic, or by the Institutional Review Board (IRB) of Billings, and other regulatory agencies as described above.

By signing this form, I have not given up any of my legal rights as a research participant. I understand that I will receive a signed copy of this authorization for my records.

\_\_\_\_\_  
Printed Name of Consenting Adult

\_\_\_\_\_  
Signature of Consenting Adult

\_\_\_\_\_  
Date