

Parents of Children Newly Diagnosed with T1DM:
Experiences with Social Support and Family Management

A Dissertation Presented

By

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Submitted to the Graduate School of Nursing
University of Massachusetts, Worcester in partial fulfillment
of the requirements for the degree of

Doctor of Philosophy

Nursing

2010

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University of Massachusetts Worcester

Graduate School of Nursing

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Acknowledgements

This dissertation work would not have been accomplished without the support, assistance and guidance of many individuals. Much gratitude and appreciation is owed to my dissertation committee. Dr. Susan Sullivan-Bolyai, my dissertation chair, deserves great thanks for her patience, her encouragement, and her confidence in me by sharing her STEP research. Dr. Carol Bova, committee member, for her quantitative expertise and support. I thank Dr. Kathleen Knafl, committee member, for her expertise in and passion for family nursing and family management.

Most importantly, I want to thank the families who opened their homes, shared their stories and briefly, their lives.

I would never have been able to complete this doctoral program without the support and encouragement of my classmates Shirley Tierney PhD, Susan Shepherd, and Chip McIntosh. My colleagues in the Nursing Department at Worcester State University unfailingly provided supportive shoulders, smiling faces and listening ears – thank you all.

Finally, my husband, Dennis, and our children, Molly, Emma and Benjamin, are owed thanks for their love, their patience, and their editing help. The support Dennis has provided has been never-ending, from being sure I was fed to being sure I stopped to smell the roses (and weed the garden). “Thank you” will never be enough.

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Abstract

The purpose of this mixed-methods descriptive study with parents of children newly diagnosed with Type 1 diabetes was to explore their experiences with peer social support following the Social Support to Empower Parents (STEP) intervention and to examine the usefulness of the Family Management Measure (FaMM) in this population. The specific aims were to describe parents' experiences with the STEP social support intervention, describe parents' day-to-day diabetes management as measured by the FaMM, describe the relationship between parental management scores in the six FaMM dimensions and the social support intervention dose used, and explore FaMM scores in relationship to parent satisfaction with the STEP social support intervention. Identified themes of availability, practical tips, and common ground resonated throughout the interviews with parents and reflected Ireys' emotional, informational, and affirmational social support framework. Regardless of the intervention dose, number of parent mentor contacts, or scores on the FaMM scales, all parents interviewed when questioned, gave a 5/5 for satisfaction with the STEP RCT, qualitatively underscoring the positive effect of the intervention.

Parents of Children Newly Diagnosed with T1DM: Experiences with Social Support and Family Management

CHAPTER I

Overview

This chapter synthesizes the literature on the state of the science regarding parental and/or family social support and day-to-day management of a child's chronic illness, including type 1 diabetes mellitus (T1DM). First, the research problem will be stated, followed by the aims of the dissertation study. Next, the background to the problem will be reviewed, including T1DM, day-to-day management, social support, peer social support interventions, family management of a child's chronic illness, and gaps in current research on peer social support for parents of children with chronic illness.

Introduction

Children in the United States are increasingly being diagnosed with T1DM. Indeed, 13,000 children are estimated to be diagnosed yearly (Doyle & Grey, 2010). The initial diagnosis requires that parents adapt to significant changes in family life, including the demands of managing this life-changing illness. Parental day-to-day management of children with T1DM requires a working knowledge of the disease process and potential complications. Families can learn to cope with the day-to-day tasks of managing the disease if they receive medical and emotional support (Doyle & Grey, 2010).

After their child's diagnosis, parents have identified needing diabetes education and social support to help them adjust to the day-to-day management of their child's chronic illness

(Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2003). A parent mentor support feasibility study assigned a parent mentor to mothers with children newly diagnosed with T1DM, providing emotional, informational and affirmational support (Sullivan-Bolyai et al., 2004). Parent mentors, mothers who had successfully raised children with T1DM, provided home visits and telephone calls to parents in the experimental arm of the study over a 6-month period. Findings from this study suggested that mothers' confidence in managing their child's newly diagnosed T1DM was improved, and their concerns and negative perceptions of the illness impact on their family were lessened by being assigned a parent mentor (Sullivan-Bolyai et al., 2004). Based on those findings, a phase 3, a randomized controlled trial (RCT) providing the same type of social support mentorship was conducted with both mothers and fathers of children newly diagnosed with T1DM (Sullivan-Bolyai et al., 2010). As part of that RCT, parents in the experimental arm received an intervention, entitled Social Support to Empower Parents (STEP), and were interviewed about their experiences in the intervention. This dissertation is the analysis of the qualitative data and the analysis of an additional family management instrument.

Therefore, the purpose of this proposed mixed-methods descriptive study was to explore parents' experiences with peer social support following the STEP intervention and to examine the usefulness of the Family Management Measure (FaMM) in this population. The specific aims of this study were to:

- 1) Describe parents' experiences with the STEP social support intervention,
- 2) Describe parents' day-to-day diabetes management as measured by the Family Management Measure (FaMM) (six dimensions: child's daily life, condition

management ability, condition management effort, family life difficulty, parental mutuality and view of condition impact),

- 3) Describe the relationship between parental management scores in the 6 FaMM dimensions and the social support intervention dose used, and
- 4) Explore FaMM scores in relationship to parent satisfaction with the STEP social support intervention.

Background

Type 1 Diabetes Mellitus

Incidence, Prevalence and Etiology

T1DM is a chronic autoimmune metabolic disorder which affects 18 million people in the United States, over two million of whom have its most severe form, childhood diabetes (also known as juvenile, type 1, or insulin-dependent diabetes) (Doyle & Grey, 2010). Incidence of T1DM in children is increasing. In the United States, the incidence rate for T1DM in children 14 years and younger, has been reported as between 11.7 and 17.8 per 100,000 per year (DIAMOND Project Group, 2006). Over the last 15 years, the annual increase in incidence of T1DM in children 0-4 years of age was 5.4% and in children 5-9 years of age was 4.3% (Patterson et al., 2009). T1DM is the most common metabolic disorder in children, second only to asthma (Centers for Disease Control [CDC, 2009]). T1DM appears suddenly, most often in childhood and young adulthood. T1DM progresses rapidly and the body's immune system destroys the pancreatic beta cells or causes them to function abnormally, eliminating or reducing the production of insulin (Doyle & Grey, 2010).

The increased incidence of T1DM in the United States cannot solely be explained by genetics; environmental factors may influence children with a genetic predisposition (Doyle &

Grey, 2010). Although the causes of T1DM are not yet completely understood, various factors have been proposed such as rapid growth in early childhood, early exposure to certain food constituents (e.g., cow's milk), enterovirus infection, chemicals, and reduced exposure in early childhood to infective agents that contribute to developing a healthy immune system (Doyle & Grey, 2010).

T1DM develops due to an autoimmune disorder in which the body destroys its own pancreatic beta cells (Atkinson & Eisenbarth, 2001; Doyle & Grey, 2010). The pancreas ceases to manufacture insulin, a hormone necessary to convert food into energy for the body (CDC, 2009). T1DM usually strikes children and young adults, although disease onset can occur at any age (Atkinson & Eisenbarth, 2001). More recently, children are being diagnosed with T1DM at a younger age (Doyle & Grey, 2010). T1DM is the leading form of diabetes in young white individuals (Dabelea, 2009) and in children under 10 years of age regardless of race or ethnicity (DIAMOND Project Group, 2006; Mayer-Davis et al., 2009).

Diabetes Management

T1DM cannot be prevented (Atkinson & Eisenbarth, 2001). Diabetes is a complex disorder, with great diversity in its pathogenesis, clinical presentations, and clinical outcomes (Mayer-Davis et al., 2009). T1DM is treated by administering insulin, monitoring blood glucose, maintaining regular exercise, and eating a healthy diet on a daily basis (Tamborlane, Boland, & Grey, 2003). Short-term complications from T1DM include severe hypoglycemia and ketoacidosis, and long-term complications include microvascular and macrovascular problems such as nephropathy, retinopathy, as well as coronary and peripheral vascular disease (Doyle & Grey, 2010). These complications can be reduced by what is referred to as intensive management (Tamborlane et al., 2003). Specifically, intensive management is defined as testing

blood glucose levels four or more times per day, injecting insulin a minimum of three times per day or using an insulin pump, adjusting insulin doses according to food intake and exercise, and following a healthy nutritional plan (American Diabetes Association [ADA], 2009; Doyle & Grey, 2010).

The Diabetes Control and Complications Trial (DCCT) Research Group conducted a 10-year study on intensive diabetes management (DCCT Research Group, 2009). The DCCT involved 1,441 volunteers with T1DM ages 13 to 39. Less than 20% of study participants were adolescents aged 13-18 (DCCT Research Group, 1993). A follow-up study, the Epidemiology of Diabetes Interventions and Complications (EDIC) concluded that intensive blood glucose control was found to reduce the risk of cardiac disease events and complications related to the eyes, kidneys, microvascular and macrovascular systems by delaying diabetes onset and slowing progression of long-term complications (DCCT, 2009; Doyle & Grey, 2010; Levine et al., 2001). For instance, risk of diabetic retinopathy was reduced by 76%, nephropathy development by 50%, and risk of neuropathy by 50% (DCCT, 2009).

Insulin administration several times per day by individual subcutaneous injections or via a continuous subcutaneous infusion is needed to maintain consistent blood glucose levels (DCCT, 2009). Monitoring blood glucose several times per day assures that levels remain within target limits to avoid hypo- or hyperglycemia (DCCT, 2009). Blood glucose levels are most commonly monitored using a handheld glucometer after obtaining a drop of blood by fingerstick (Doyle & Grey, 2010). Since blood glucose levels are affected by dietary intake, physical activity, illness, growth spurts, and puberty, insulin dosage must be adjusted accordingly. Blood glucose levels decrease with increased physical activity, increase with metabolic increases due to febrile illnesses, and increase due to hormonal changes associated with growth spurts and

puberty (Doyle & Grey, 2010). Tight diabetes control is defined by the American Diabetes Association (ADA) (ADA, 2009) as maintaining preprandial blood glucose between 70-130 mg/dl, postprandial blood glucose less than 180 mg/dl, and glycosylated hemoglobin (hemoglobin A1c) less than 7.0%.

Managing this chronic illness through education is a key step in improving health outcomes and quality of life (Fisher, Thorpe, DeVellis & DeVellis, 2007; Funnell et al., 2009). Individuals with T1DM must adopt self-management behaviors such as healthy eating, being physically active, monitoring blood glucose, and recognizing the onset of high or low blood glucose levels. Healthy eating involves counting carbohydrate intake to determine insulin dose (Funnell et al., 2009). Children with T1DM, whose care is primarily managed by their parents, must adhere to scheduled blood glucose checks, insulin injections, and meal and snack times. Even small changes from the schedule of a child's diabetes care plan can result in hypoglycemia or hyperglycemia (Doyle & Grey, 2010).

Young children diagnosed with T1DM are unable to independently self-manage due to childhood developmental considerations and limited self-care abilities (Mednick et al., 2007; Silverstein et al., 2005). Thus, parents must manage this chronic illness. A family whose child is diagnosed with a chronic illness must learn the treatment regimen and how to incorporate it into everyday life (Knafl & Deatrick, 2003; Knafl & Gilliss, 2002; Sullivan-Bolyai et al., 2003).

After Diagnosis: Adapting to Day-to-Day Management

The shock of initial diagnosis requires that parents adapt to significant changes in family life and deal with the physical impact of the child's serious chronic illness (Grey, Knafl, & McCorkle, 2006; Knafl & Deatrick, 2003; Silverstein et al., 2005). Parents of children with T1DM must quickly adapt to incorporating the critical components of day-to-day diabetes

management. The ability of the family to provide the child's care varies depending on available educational, economic, and emotional resources (Grey et al., 2006; Knafl & Gilliss, 2002). Families with higher education, more financial stability, and more resilient emotional resources may receive the diagnosis and manage the new responsibility well (Grey et al., 2006). In a study with caregivers of children aged less than 9 years with T1DM ($n=73$) (Stallwood, 2006), diabetes knowledge was assessed using The Michigan Diabetes Research Training Center Knowledge Test (MDRTC). The range of possible scores was 0 to 23. Higher scores indicated higher levels of diabetes knowledge ($M=17.2, SD=3.1$). Results from the analysis indicated that higher scores on the MDRTC were significantly related to higher levels of income ($r=.40, p<.01$). In addition, married caregivers ($M=18.3$) had higher levels of knowledge than unmarried caregivers ($M=15.8; t=2.3, p<0.05$) (Stallwood, 2006). Families with known risk factors for poor diabetes control, including single-parent families, those living in poverty, and parents coping with other major stressful life events, may have more difficulty adapting to the required changes in care (Grey & Tamborlane, 2003; Grey et al., 2006).

Parental day-to-day management of children with T1DM requires a working knowledge of the disease process and potential complications. The parent's goal is to maintain the child's blood glucose level in the acceptable range. Managing the care of young children with T1DM requires the parents' constant vigilance (Sullivan-Bolyai, Deatrick et al., 2003). This central theme emerged from a qualitative study of 28 mothers of children less than 4 years of age. The children had been diagnosed with T1DM for at least 3 months and had a mean duration of illness of 1.25 years. Parental involvement in diabetes management has consistently been viewed as an important determinant of positive child-health outcomes (LaGreca et al., 1995). This is

especially so with the increase in medical technology (insulin pumps) and emphasis on tighter blood glucose control at younger ages (Streisand, Swift, Wickmark, Chen & Holmes, 2005).

During the vulnerable time following diagnosis, parental anxiety, depression, and lack of confidence can affect their ability to implement the child's medical regimen (Horsch, McManus, Kennedy, & Edge, 2007; Streisand et al., 2008). Parents of children newly diagnosed (1-4 weeks) with T1DM were screened for depression and anxiety. Over 74% of this group met criteria for mild depression and 54% reported clinically significant levels of anxiety at the time of their child's diagnosis (Streisand et al., 2008). Even years after the diagnosis, parents may be concerned about the impact of T1DM on their child. Among mothers (N=60) whose children had been diagnosed with T1DM on average for 35.2 months, 41.7% worried about the child's health being permanently damaged and 28.3% worried about the child's future in relation to diabetes (Horsch et al., 2007).

Parents must not only deal with the intensive management of their child's condition, but also with the normal developmental challenges of childhood and adolescence (Doyle & Grey, 2010). In a 2002 study, parents of children newly diagnosed with T1DM expressed concerns about managing issues such as toilet training, communication with daycare providers, preschool or school staff, and finding a babysitter (Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2002). Others caring for the child must be educated, usually by the child's parents, in day-to-day diabetes management.

Both mothers and fathers of children newly diagnosed with T1DM have reported feeling alone, isolated, and abandoned (Wennick & Hallstöm, 2006a). A sample of 23 Swedish parents of children diagnosed with T1DM in the previous 1-3 months reported worry, lack of confidence, and stress. Mothers of children with chronic illnesses, including T1DM, historically provide the

majority of hands-on care (Sullivan-Bolyai, Deatrick et al., 2003). Mothers have reported that fathers are a source of emotional support. Fathers of newly diagnosed children have described being unprepared for the type of care and time required to manage T1DM (Sullivan-Bolyai, Rosenberg & Bayard, 2006).

Social Support

Concept of Social Support

Social support is a concept generally understood as perceived help from others during a difficult life situation (Eckenrode & Gore, 1981). One early definition of social support was the individual belief that one is cared for and loved, esteemed and valued, and belongs to a network of communication and mutual obligations (Cobb, 1976). The concept of social support was intensely studied by a myriad of disciplines, including nursing. Observational studies suggested that socially isolated individuals had poor outcomes (Norbeck, 1981). One commonality of these concept studies is that social support is multidimensional with no universally accepted definition or conceptualization (Dalgard, 2009).

“Social support” is a term used frequently in the nursing literature (Achwartz-Barcott & Hesook, 2000; Craig, Weinert, Walton, & Derwinski-Robinson, 2006; Fingeld-Connett, 2005; Mercer, May, Ferketich, & DeJoseph, 1986). Simply put, social support is the network of individuals (family, friends, and community members) who provide information and/or physical or emotional comfort during stressful times (Fingeld-Connett, 2005). The concept is composed of both instrumental (actions) and emotional aspects and may result in improved mental health (Fingeld-Connett, 2005). Another conceptualization of social support includes attachment/intimacy, social integration, nurturing behavior, and self-worth (Craig et al., 2006).

Other researchers consider social support an interrelated cluster of concepts (Achwartz-Barcott & Hesook, 2000) as well as the amount of help received, the satisfaction with that help, and the person(s) providing that help (Cohen, Gottlieb, & Underwood, 2001). The strongest associations between social support (particularly emotional support) and health outcomes are seen in relation to psychological well-being (Cohen et al., 2001).

Protective Functions of Social Support

Positive social support may have a protective function. It may buffer stress, play a moderating role in health maintenance, and help recovery from illness (Norbeck, 1985). Social support may help in managing and adjusting to chronic illness (Lindsey & Yates, 2004) as well as having a “direct impact” on the uncertainty of illness by reducing perceived complexity and having an effect on predicting symptom patterns (Mishel & Braden, 1988). The perceived availability of social support, often used in a broad sense, is known to promote health and well-being (Cohen et al., 2001).

Social support for parents of children with a chronic illness can potentially decrease parental distress (Ireys, Chernoff, DeVet & Kim, 2001; Ireys, Chernoff, Stein, DeVet & Silver, 2001; Ireys, Sills, Kolodner & Walsh, 1996). An RCT that tested a 15-month social support intervention for mothers (N= 48) of children with Juvenile Rheumatoid Arthritis provided emotional, informational and affirmational support from peer mentors (Ireys et al, 1996). Results demonstrated a significant decrease in scores on the anxiety subscale of the Psychiatric Symptom Inventory (PSI) for the intervention group (t (df not reported) = 2.05, $p=.05$). During the intervention period, mothers in the intervention group had a decrease in reported mental health symptoms (t (df not reported) = 1.79, $p = .08$) while the number remained the same in the control group (Ireys et al., 1996). In 2001 a review was conducted of three social support

intervention RCTs for mothers of children with chronic illnesses (Ireys, Chernoff, Stein et al., 2001). Parents received face-to-face social support by network mothers who provided informational, affirmational and emotional support to mothers of school aged children with chronic illnesses. These studies had samples ranging from 53 to 365 mothers. Intervention durations were 12 or 15 months long. Mothers in both the control and intervention groups were stratified into low-anxiety and high-anxiety subgroups pre-intervention using the Psychiatric Symptom Index (PSI). PSI scores of mothers in the intervention high-anxiety subgroup decreased compared to PSI scores of mothers in high-anxiety subgroup in the control group. The study findings suggested that this type of support intervention could decrease maternal anxiety. This type of intervention may also enhance mothers' perceived availability of social support (Ireys, Chernoff, DeVet et al., 2001; Ireys, Chernoff, Stein et al., 2001).

Modes of Social Support

Social support is considered in the theoretical nursing literature to have three vital components: perceived need, social network, and climate (or environment) (Ahern & Hendryx, 2005; Ashton et al., 2005; Bailey & Stewart, 2006; Bogossian, 2007; Finfgeld-Connett, 2005; Hoekstra-Weebers, Jaspers, Kamps, & Klip, 2001; Hupcey, 1998; Langford, Bowsher, Maloney, & Lillis, 1997; McEwen, 2002; Schaffer, 2009). Perceived need – recipients acknowledging the need and being willing to accept support - is necessary for social support to be effective (Finfgeld-Connett, 2005). Social networks are referred to as the ties and relationships that an individual maintains (Bogossian, 2007). The social network and climate comprise the individuals and the atmosphere that contribute to individuals' supportive behaviors. The social climate refers to the common context in which the recipient and the provider of support have shared similar challenges (Finfgeld-Connett, 2005).

Supportive behaviors from others are referred to as physical support, emotional (symbolic) support, instrumental (tangible, material) support, and reciprocal support (Schaffer, 2009). Social support is a dynamic process that includes the interactions of the provider and recipient (Hupcey, 1998). In Norbeck's model (1982), social support is incorporated into practice with emphasis on the properties of the person, properties of the situation, need for, and availability of social support (McEwen, 2002).

Individuals may ask for or be referred to social support programs in four types of situations: life transitions (i.e., pregnancy and aging), changing family role performance (a child with developmental disabilities or caregiver for a family member), health behavior (adherence to health practices) or crisis, or illness behavior (hospitalization, acute, chronic or life-threatening illness) (Norbeck, 1988). In these situations, nurses can intervene to promote or strengthen social support resources for their clients (Schaffer, 2009). Clinicians should assess their clients for the level of perceived social support, availability of support, actual support received, costs of support, and changes in support over time. Social support may be provided by families, professionals, members of a social network, or peers. A peer can be an individual of the same age, demographic, or experience. This study focused on a parental peer social support.

Peer Social Support for Parents of Children with Chronic Illness

Parents of children diagnosed with chronic illnesses or conditions have been the focus of peer social support research. These conditions have included childhood cancer (Hoekstra-Weebers et al., 2001), autism (Symon, 2005), juvenile rheumatoid arthritis (Ireys, Chernoff, Stein, et al., 2001; Ireys, Sills, et al., 1996), T1DM (Chernoff, Ireys, DeVet, & Kim, 2002; Sullivan-Bolyai et al., 2004), congenital heart disease (Tak & McCubbin, 2002), developmental delays and chronic illnesses (Ainbinder et al., 1998), moderate to severe asthma, sickle cell

anemia, cystic fibrosis (Chernoff et al., 2002), special health care needs such as lung disease that required technology dependence (Nicholas & Keilty, 2007), and “diverse chronic health conditions” (Silver, Ireys, Bauman, & Stein, 1997). Sample sizes ranged from 3 families (Symon, 2005) to 365 mothers (Silver et al., 1997). Methods of inquiry included quantitative (Tak & McCubbin, 2002; Hoekstra-Weebers et al., 2001), qualitative (Ainbinder et al., 1998), and interventions (Nicholas & Keilty, 2007; Sullivan-Bolyai et al., 2004). Common measures used in these studies were the General Health Questionnaire (GHQ), the Social Support List-Interactions (SSL-I), and the Social Support List-Discrepancies (SSL-D) (Ainbinder et al., 1998; Chernoff et al., 2002; Hoekstra-Weebers et al., 2001; Nicholas & Keilty, 2007; Symon, 2005; Tak & McCubbin, 2002).

Tak and McCubbin (2002) (N= 92) analyzed family stress, perceived social support, and coping following the diagnosis of a child’s congenital heart disease. They reported that perceived social support mediated between family stress and parental and family coping ($\beta = .39, p < .001$). Hoekstra-Weebers et al. (2001) assessed psychological adaptation and social support of parents of pediatric cancer patients (N= 128). In this study, parents received most support at diagnosis with fathers ($F=8.35, p < .001$) and mothers ($F=20.87, p < .001$) receiving less support over time.

Ainbinder et al. (1998) conducted a qualitative descriptive study to explore mothers’ and fathers’ ($n = 24$) experiences with a parent-to-parent program for families with children with special needs. The children’s diagnoses included cerebral palsy, epilepsy, developmental delays, mental retardation, learning disabilities, hearing and/or vision deficits, and several chronic illnesses. They reported that a successful parent-mentor relationship depended on perceived “sameness,” a situational comparison that enabled learning and growth, around-the-clock availability of support, and mutuality of support. Perceived sameness was found to be the most

basic principle of self-help support. This perception was established because the support giver (parent mentor) typically had experienced the same challenges as the support recipient (parent of newly diagnosed child) (Ainbinder et al., 1998).

Peer Social Support Interventions for Parents of Children with Chronic Illnesses

The remaining studies reviewed on peer support for parents of children with chronic illnesses were interventions (Chernoff et al., 2002; Ireys, Chernoff, DeVet et al., 2001; Ireys et al., 1996; Nicholas & Keilty, 2007; Silver et al., 1997; Sullivan-Bolyai et al., 2004; Sullivan-Bolyai et al., 2010; Symon, 2005). These studies had a variety of designs including quasi-experimental (Nicholas & Keilty, 2007), single-case analysis (Symon, 2005), and several RCTs (Chernoff et al., 2002; Ireys et al., 1996; Ireys, Chernoff, DeVet, et al., 2001; Silver et al., 1997; Sullivan-Bolyai et al., 2004). The social support interventions were provided by parent peers, i.e., parents of children diagnosed with the same health problem. Parent mentor support ranged from 1 week (Symon, 2005) to 15 months (Chernoff et al., 2002). The smallest study sample was 3 families (Symon, 2005) while the largest was 365 mothers (Silver et al., 1997). Parents were offered social support at various times following a child's diagnosis with a chronic illness, ranging from immediately following (Sullivan-Bolyai et al., 2004) to 5 years afterward (Silver et al., 1997). Across all studies, parents reported feeling less isolated, identifying strategies to help with adjustment, and reduced mental health symptoms, including decreased stress (Chernoff et al., 2002; Ireys, Chernoff, Stein, et al., 2001; Ireys et al., 1996; Nicholas & Keilty, 2007; Sullivan-Bolyai et al., 2004; Sullivan-Bolyai et al., 2010; Symon, 2005).

Nicholas and Keilty (2007) conducted a quasi-experimental pilot intervention ($n= 34$ parent-peer dyads) to explore the effect a social support program on parental coping, social isolation and illness intrusion with parents of technology-assisted children with chronic lung

disease. After matching parents on child's age, condition severity and duration of illness, parent dyads communicated for a minimum of four months by phone, email, face-to-face or a combination. Pretest-posttest differences were not significant (*t* test scores not reported, *p* values 0.3-0.53) for perceived social support from friends and family (social isolation), coping, and meaning of illness (illness intrusion). Subscale analysis for caregiver stress, change in commitment and secondary illness appraisal suggested trends (*p*= 0.079) for improvement over time. The qualitative findings suggested the intervention provided communication with someone who understood what the caregivers were experiencing, thus it decreased their social isolation and enhanced learning. Limitations of this study were that there was no formalized training for the mentors and no randomization. However, the authors stated that the qualitative findings indicated that social support may be beneficial to families raising children with special healthcare needs (Nicholas & Keilty, 2007).

Several parental peer social support intervention studies (Chernoff et al., 2002; Ireys, Chernoff, DeVet, et al., 2001; Ireys et al., 1996; Silver et al., 1997; Sullivan-Bolyai et al., 2010) have been framed by Ireys' Parental Support Model (Ireys, Chernoff, DeVet, et al., 2001). Ireys et al. (2001) defined social support as information leading people to believe they are esteemed and valued and that they belong to a network of mutual obligations. In his framework he used three essential social support components: informational, affirmational and emotional. The framework will be described in detail in Chapter II. The RCT intervention studies (Ireys, Chernoff, DeVet, et al., 2001; Ireys et al., 1996; Silver et al., 1997; Sullivan-Bolyai et al., 2004) have been focused on parents of children with diabetes, autism, special needs and chronic lung disease. Providing parents peer social support resulted in reduced feelings of isolation, decreased anxiety, and feeling understood.

Ireys' seminal RCT social support intervention was conducted (over the course of 15 months) using peer parent mentors for mothers ($N=52$) of children with juvenile rheumatoid arthritis (JRA). The duration of illness was 3 years for the majority of children. The total number of reported mental health symptoms as measured by the PSI, which measures parental stress related to caregiving, decreased in the experimental group ($n = 23$) while remaining the same in the control group ($n = 19$) (t (df not reported) = 1.79; $p = .08$) (Ireys et al., 1996). Mothers in the experimental arm also self-reported lower levels of anxiety compared to those in the control arm (t (df not reported) = 2.05, $p = .05$).

In a 12-month RCT with 365 mothers of children with ongoing health conditions (average 5 years since diagnosis), posttest scores measuring depression and psychological distress of the intervention and control groups did not differ significantly between groups (Silver, et al., 1997). On the depression subscale both the intervention and control groups improved over time (intervention group pretest score of 23.8 decreased to 22.1; control group 20.8 pretest decreased to 19.6 [F not reported]; $p < .01$). Scores in the anger subscale for the intervention group showed a significant decrease (intervention group pretest score of 29.0 decreased to 26.7; control group pretest 23.9 increased to 25.8 [F not reported]; $p < .01$) (Silver et al., 1997).

Although intervention effects were not related to participation level, illness-related, and/or sociodemographic factors, the authors reported a significant interaction with stressful life events (SLE) (Silver et al., 1997). With mothers who reported more than 5 SLEs in one year, a significant interaction effect of group assignment was reported for posttest scores on the anxiety subscale ($F = 4.61$; $p < .05$). This result suggested that the intervention effectively reduced anxiety symptoms by acting as a moderator variable in the subgroup of mothers who reported relatively higher life stress (Silver et al., 1997).

In the studies based on Ireys' Parental Support Model, peer social support was provided by parent mentors whose children had chronic illnesses (Ireys, Chernoff, DeVet, et al et al., 2001; Ireys et al., 1996; Sullivan-Bolyai et al., 2004). Peer social support was defined as providing information that allowed an individual to perceive that they were valued and respected (Ireys et al, 1996).

Several peer social support intervention research studies for parents have focused on using experienced parents (with at least one year duration of illness) to assist parents of children newly diagnosed with a chronic illness. Experienced parents provided three types of support: informational, affirmational, and emotional (Ireys et al, 1996; Ireys, Chernoff, DeVet, et al., 2001; Sullivan-Bolyai et al., 2004). Informational support was defined as sharing information about the disease process and management, practical tips, and general coping (Ireys et al., 1996). Ireys et al. (1996) stated that affirmational support was characterized by parent mentors praising successes, competencies, providing positive feedback, and validating their experience. Emotional support was provided by being available to listen to parental concerns and communicating an understanding of these concerns (Ireys et al., 1996).

These three types of parental peer support were applied in a "family-to-family network" randomized intervention for 161 parents of children with asthma, sickle cell anemia, cystic fibrosis, and T1DM (Ireys, Chernoff, DeVet, et al., 2001). The goal of the Ireys' intervention was to improve maternal psychological adjustment to their children's disease by decreasing anxiety and depression. These children were not newly diagnosed with the chronic illness. Parents were randomized into experimental ($n = 86$) and control ($n = 75$) groups. Both groups included mothers characterized at baseline as either highly anxious or less anxious by the 11-item anxiety subscale of the Psychiatric Symptom Index (PSI) (Ireys et al., 2001). Each mother

in the experimental group was matched with an experienced “network” mother who had been educated with a social support curriculum that included active listening skills, reflection, and story swapping (Ireys et al., 2001).

At the end of the 12-month intervention, participants in the experimental group reported significantly lower levels of anxiety (mean PSI = 26.4) compared to those in the control group (mean PSI = 31.6; $F = 5.07$, $p = .03$). Mothers categorized as highly anxious also had decreased PSI scores following the intervention ($F = 5.07$, $p = .03$). The authors concluded that the intervention may be especially effective for mothers who are anxious or who themselves are in poor health (Ireys et al., 2001).

Peer Social Support Interventions for Parents of Children with T1DM

In 2004, a feasibility RCT: Helping Other Mothers Effectively Work at Raising Young Children with Type 1 Diabetes (HOMEWARD) was conducted for mothers ($N = 42$) of children newly diagnosed with T1DM (Sullivan-Bolyai et al., 2004). Using Brootens’ model (specifically the emotional support component of the quality-cost model) and the parent support curriculum developed by Ireys et al., parent mentors provided informational, affirmational, and emotional support to test the hypothesis that the intervention could reduce parental concern, stress, and anxiety (Sullivan-Bolyai et al., 2004).

Parent mentors were carefully selected and received formal curriculum training. They made visits to the participants’ homes (range of 1-8 visits) in addition to phone calls and/or email contact over the 6-month trial period. During the interactions parent mentors reinforced diabetes management information introduced by the diabetes team during the child’s short hospital stay. This information included effective use of the diabetes team, practical illness-related information, and community resources. Parents enrolled in the intervention group were

also provided information on how to incorporate day-to-day illness management into family life and opportunities to talk with parent mentors who validated feelings, reassured parents, and provided emotional support (Sullivan-Bolyai et al., 2004).

The mean intervention dose was 7.6 hours (range= 3.5-14.6 hours). Outcomes were measured at baseline, 1 and 6 months (Sullivan-Bolyai et al., 2004). The instruments used to measure parent concern (Banion's Diabetes Management Concern Questionnaire), parent confidence (Ireys' Parental Confidence Questionnaire), parent perception of the disease's impact on the family (Stein's Impact on the Family Scale), and parent perception of community resources (Home Care Resources Questionnaire) all had acceptable reliability and validity (Sullivan- Bolyai et al., 2004).

Mothers who received the intervention had fewer diabetes-related concerns ($F= 4.00$; $p =.02$), more confidence ($F= .82$; $p =.44$) and knowledge of homecare resources ($F= 2.98$; $p =.06$) than mothers in the control group. They perceived a less negative impact of the illness on the family ($F=3.15$; $p =.05$) than mothers in the control group. Mothers in the intervention group also identified more resources at 6 months than the control group (Sullivan-Bolyai et al., 2004).

Qualitative data revealed that the parents felt empowered by participating in the program, which reinforced how much they had grown in managing their child's chronic illness. Several mothers reported that the parent mentors helped them see the "big picture," learn practical ways to fit diabetes into family life, and not let the child's illness dictate life (Sullivan-Bolyai et al., 2004). The data suggested that social support provided by parent mentors for mothers of young children newly diagnosed with T1DM had the potential to decrease parental concern, increase feelings of confidence, and provide parents with much needed practical information on managing their child's disease on a daily basis (Sullivan-Bolyai et al., 2004). This type of peer support also

appeared to provide emotional and affirmational support and to validate mothers' concerns with the day-to-day illness-related management of these young children. In summary, the findings from Sullivan-Bolyai et al.'s feasibility study (2004) suggested that parent mentors positively affected parental concern, confidence, perceived impact of diabetes on the family, and perceived available social support.

Expanding upon the results of the HOMEWARD feasibility study, a phase III (12 month) RCT (Social Support to Empower Parents [STEP]) was conducted including both mothers and fathers as mentors and subjects (Sullivan-Bolyai et al., 2010). Mothers of children newly diagnosed with T1DM (N= 60) were randomized and assigned to a parent mentor (n= 32) or the control group (n=28). Members of the control group were provided with a telephone number of an experienced parent (not trained to provide social support) to call if needed. Both groups also received traditional medical support from a diabetes team. Fathers were also part of the study, assigned to a parent mentor (n=19) or the control group (n=9) depending upon the mother's randomization. The STEP study's primary aim was to evaluate the intervention effect on parental concern, worry, distress, strain, confidence, impact of the illness on the family, and perception of support. These outcomes were assessed at 3, 6, and 12 months after diagnosis. A secondary aim of the study was to describe the experiences of mothers and fathers receiving the intervention as well as the parent mentors' experiences providing the intervention (Sullivan-Bolyai et al., 2010).

The findings for the mothers included no differences between the two groups at 3, 6, and 12 months in parental concern, confidence, worry, impact on the family, or perceived social support. Each parent in the intervention arm of STEP had an average of 5 contacts (range 1-25) with the parent mentor, primarily via telephone following the initial face-to-face

visit ($n = 41$ visits). Each parent contact lasted an average of 63 minutes (range 5-195 minutes). Although not statistically significant, parents' perceptions of parent mentor social support increased over time (Sullivan-Bolyai et al., 2010). The lack of statistical significance could be attributed to several issues. First, randomization did not work for birth order, with more mothers in the experimental group having first-born children newly diagnosed with T1DM. It is possible they had ongoing heightened levels of stress throughout the clinical trial due to being new parents. Second, the control group (many of whom were disappointed to be randomized to that group) may have sought out informal social support in their communities. Third, at the end of the study it was noted by diabetes team staff that families they felt were too overwhelmed were not referred. Thus, those parents who may have most benefited from the intervention were excluded.

This dissertation study focused on the qualitative component of the STEP RCT. As the results of the STEP RCT showed no significant difference between the control and experimental groups, the analysis of the qualitative data may provide new insights into possible positive and negative issues with the STEP intervention. Since the day-to-day management of a child's chronic illness was underscored as an important task for parents in both HOMEWARD and STEP, this chapter will next critically review the family management literature that informed this study.

Family Management

Family management is defined as the process of family adaptation to a member's illness (Knafl & Gilliss, 2002). Families have been characterized as typically rising to the challenges of managing a chronic illness and incorporating day-to-day tasks into the family routine. Adaptation to a family member's chronic illness is a process, whereby families use

different strategies to incorporate illness management into everyday life (Knafl & Gilliss, 2002). Several studies have focused on the normalization of chronic illness into family life (Gallo & Knafl, 1998; Gravelle, 1997; Knafl, Breitmayer, Gallo, & Zoeller, 1996; Wennick & Hallstöm, 2006b). Wennick & Hallstöm, in a qualitative study with families of children newly diagnosed with T1DM (N = 38 [11 mothers, 10 fathers, 11 children diagnosed with T1DM, 6 siblings]), reported the primary theme of living a “different but ordinary life” 1 year after diagnosis (Wennick & Hallstöm, 2006b, p. 302). The authors conducted interviews with children with T1DM, their parents, and their siblings one year following diagnosis. Themes that emerged during the data analysis were the illness being interwoven into their daily lives, acceptance but frustration, the invisibility of the illness, and an underlying confidence but being insecure (Wennick & Hallstöm, 2006b).

As described by Gallo and Knafl (1998), parents use three approaches to manage children’s care: strict adherence, flexible adherence and selective adherence. Strict adherence is characterized by parents rigidly following the prescribed treatment plan. Flexible adherence is described as parents allowing some modification of or relaxation with the prescribed regimen. Selective adherence may be described as parents developing an alternative or unorthodox approach to children’s treatment plan (Gallo & Knafl, 1998). Sullivan-Bolyai, Knafl, Deatrick and Grey (2003) reported that mothers raising their children (aged 0-4 years) newly diagnosed with T1DM (N=28) used two management approaches: strict and flexible adherence. All children had been diagnosed with T1DM 3 to 33 months prior to the interviews (mean duration of illness=1.25 years). Mothers reported using strict adherence in the early months following diagnosis, worked closely with the diabetes team, including frequent consultation and telephone contact with diabetes nurse educators (Sullivan-Bolyai, Knafl et al., 2003). Mothers reported that

it took 6 to 12 months after diagnosis for them to feel confident with the treatment regimen. As confidence levels increased, mothers moved into a more flexible adherence, and reported modifying treatment regimens and fewer consultation calls to the diabetes team (Sullivan-Bolyai, Knafl et al., 2003). In this study, no mothers could be categorized as using selective adherence. Mothers followed the recommended T1DM treatment regimen, as the data suggested there is considerable day-to-day work required for a young child with T1DM.

The focus of this study was limited to parents' (mothers' and fathers') roles in family management. As described in a review of adult and pediatric family caregiving literature, a parent of a child with a chronic illness is responsible for managing the illness, identifying and accessing community resources, maintaining the family unit, and maintaining "self" (Sullivan-Bolyai, Sadler, Knafl, & Gilliss, 2003). Managing the illness includes knowing about the illness and treatment plan, including daily hands-on care and interpretation of signs and symptoms of complications. In addition, parents must educate others to care for their child. Young children require constant supervision. Children diagnosed with T1DM require specialized care by those knowledgeable or willing to be educated in the day-to-day management of T1DM. These resources may include respite care or specialized day care. Identifying, accessing, and coordinating resources are tasks necessary to meet the unique needs of the child and other family members (Sullivan-Bolyai, Sadler et al., 2003). The authors described "maintaining the family unit" in the literature as nurturing the family as a whole, balancing the child's demands with those of the family, and nurturing the relationship with the parental partner (Sullivan-Bolyai, Sadler et al., 2003).

Mothers and fathers have different roles in the day-to-day management of a child's chronic illness. They have described management tasks being divided depending upon parents'

work schedules (Sullivan-Bolyai, Rosenberg & Bayard, 2006). Fathers have expressed the need to “stay in the loop” to maintain the skills required for management. However, much of the day-to-day care has been reported to fall on mothers, who are more often physically responsible for required tasks (Landolt, Ribi, Laimbacher, Vollrath, Gnehm, & Sennhauser, 2002; Sullivan-Bolyai et al., 2002). With T1DM, mothers have reported that they have the major responsibility for meal planning and ongoing monitoring (Sullivan-Bolyai et al., 2006).

Although some fathers may not play as active a role as mothers in the day-to-day management of a child’s chronic illness, they have reported providing much-needed emotional support for mothers (Dashiff, Morrison, & Rowe, 2008). Sullivan-Bolyai et al. (2006) conducted a qualitative descriptive study with 14 fathers of children with T1DM. Open-ended interviews were conducted to provide rich, comprehensive descriptions of parenting a child with T1DM. Sullivan-Bolyai et al (2006) reported that fathers of children with T1DM changed work hours to be present at children’s social or sports activities. They also used cellphones to stay in touch with their families while at work or traveling. Parents described coordinating management by discussing care decisions (Sullivan-Bolyai et al., 2006).

Family Management Style

Family management styles are defined as the different types of family responses to a chronic childhood illness (Knafl et al., 1996). The day-to-day management styles of families in which children have a chronic illness have been conceptualized in the Family Management Style (FMS) Framework (Gallo & Knafl, 1998; Knafl & Deatrick, 1990, 2003; Knafl et al., 1996). This framework was based on predominantly qualitative data from a mixed method study. The authors gathered data from 63 families (200 family members, including mothers, fathers, children with a chronic condition, and their healthy siblings) with a school-aged child whose

chronic condition was not life threatening. These data provided the basis for the development of the components of the FMS Framework (Knafl, Deatrick, & Gallo, 2008).

The FMS Framework conceptualizes the various ways in which families define and manage illness-related demands and the resulting consequences for family life (Knafl et al., 1996). The framework has three major components: 1) definition of the situation, 2) management behaviors, and 3) perceived consequences. The framework has eight dimensions: child identity, illness view, management mindset, parental mutuality, parenting philosophy, management approach, family focus, and future expectations (Knafl et al., 1996). These dimensions were defined in a later study (Knafl et al., 2008). *Child Identity* refers to the parents' views of the child and the extent to which they focus on illness or normalcy, capabilities or vulnerabilities. *Illness View* reflects the parents' beliefs about the cause, seriousness, predictability, and course of the illness. *Management Mindset* is the parents' views of the ease or difficulty of carrying out the treatment regimen and their ability to manage effectively.

Parental Mutuality refers to parents' beliefs about the extent to which they have shared or discrepant views of the child, the illness, their parenting philosophy, and their approach to illness management. *Parenting Philosophy* reflects the parents' goals, priorities, and values that guide the overall approach and specific strategies for illness management. *Management Approach* describes the parents' assessment of the extent to which they have developed routine and related strategies for managing the illness and incorporating it into family life. *Family Focus* refers to the parents' assessment of the balance between illness management and other aspects of family life. *Future Expectation* describes parents' assessment of the illness implications (Knafl et al., 2008). These dimensions have been combined to describe response to a family member's chronic illness.

Over the past 20 years this body of research has led to the description of five response patterns to chronic illness, or five family management styles (FMS): Thriving, Accommodating, Enduring, Struggling, and Floundering. These patterns represent the types of management styles parents used in their daily lives to deal with their child's chronic illness (Knafl et al., 1996).

Thriving was described as life going on as before, a confident management mindset of expected and unexpected illness demands and competent self-care behaviors. Families with a Thriving FMS dealt with the child's illness and did not let the illness define who they are as a family.

Families who used an *Accommodating* FMS were characterized by the word "usually" in that the child identity and illness view often, but not always, reflected the "thriving" style. These families had greater difficulty with day-to-day management of the child's chronic illness. *Enduring* management style was characterized by variable views of illness and self, with a protective parent philosophy and management approach. Families with an Enduring FMS had great difficulty managing the child's illness and expressed feeling burdened.

Struggling FMS was variable with child identity, illness and self-views; mothers considered the illness burdensome while fathers may have had a more confident management mindset. These families often experienced parental conflict regarding illness management. Finally, *Floundering* management style was characterized by the child view being tragic, the illness view being serious, and a reactive management approach. These families often experienced confusion and had an overall negative and uncertain view of the child's illness (Knafl et al., 1996). These family management styles have been used by this group of researchers to develop an instrument, the Family Management Measure (FaMM), to measure family management in the dimensions of Child Identity, Concern, Difficulty, Effort, Manageability, and

Parental Mutuality (Knafl et al., 2008). This measure was used in the dissertation study and will be described in detail in Chapter III.

The FMS framework may be useful to describe family efforts to manage their child's chronic illness (Deatrick, Thibodeaux, Mooney, Schmus, Pollack, & Davey, 2006). One possible use of FMS may be to classify families prior to an intervention, thus determining for which family an intervention would be more effective (Alderfer, 2006). For example, the FMS framework has been proposed to better understand the experience of families who have a child with cancer and to tailor interventions for the family during the child's cancer illness trajectory (Deatrick et al., 2006; Nelson, Deatrick, Knafl, Alderfer, & Ogle, 2006).

Gaps in the Current Research

Peer social support interventions have the potential to use health services more appropriately, enhance communication, and increase knowledge (Stewart et al., 1997). However, the available models of peer social support reviewed in the literature might not be effective for all people and conditions (Armour, Norris, Jack, Zhang, & Fisher, 2005; Cole & Chesla, 2006; Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004; Gallant, 2003; Hoey, Ieropoli, White, & Jefford, 2008; Nicholas & Keilty, 2007). In an extensive review of 100 studies, social support interventions were found to be useful overall (Hogan, Linden, & Najarian, 2002). The interventions were categorized into three groups: (1) group vs. individual, (2) professionally led vs. peer-provided, and (3) increasing social network or perceived support vs. building social skills to facilitate creating support networks. The majority of interventions using individual peer social support (9/14) showed favorable outcomes. An important aspect of these positive outcomes was the emphasis on similarity between the provider of and recipient of support. However, the evidence was insufficient at that time to indicate which interventions worked best

for which problems or conditions (Hogan et al., 2002). Similarly, in the STEP study (Sullivan-Bolyai et al, 2010) nonsignificant finding contrast with anecdotal comments expressed by parents in the experimental arm of the study. Thus, qualitative information from the dissertation study may help guide further social support research for families with children newly diagnosed with T1DM.

Intervention research on families of children diagnosed with T1DM reveals that family management patterns need to be assessed soon after the diagnosis (Cole & Chesla, 2006). Thus, nurses initially working with these families must provide early assessment and individualized interventions (Cole & Chesla, 2006). However, the process of matching peer mentors and parents is challenged by scheduling difficulties and personality incompatibility (Nicholas & Keilty, 2007). These challenges and the need for early assessment and intervention highlight the need for future research formulating optimal matching strategies to ensure best practices in peer support (Alderfer, 2006). Providing opportunities for parental peer social support in the population with the life-changing diagnosis of T1DM may enhance adjustment for both the child and family.

To fill these gaps in knowledge, this proposed family-related research study describes parents' experiences with the parental peer support intervention (STEP). In addition, the inclusion of the supplemental measure (FaMM) may provide a more precise lens into day-to-day management for families raising children newly diagnosed with T1DM. These quantitative data may refine the parent-mentor intervention, thus informing future social support research.

CHAPTER II

CONCEPTUAL FRAMEWORK

Introduction

The framework for this mixed methods, descriptive study was an adaptation of Ireys' Social Support Framework (Ireys, Chernoff, Stein, DeVet, & Silver, 2001). A conceptual framework is defined as an abstract, logical structure that guides development of a study (Burns & Grove, 2005). Qualitative research is often guided by a model that allows new concepts and relationships to emerge as abstract themes develop (Lincoln & Guba, 1985). Ireys' social support framework describes how the intervention of parent mentors can affect the mental health of parents, shape the family's social and psychological environment and resources, and affect the child's adjustment (Ireys, Chernoff, Stein, et al., 2001). Ireys and colleagues define social support as "information leading people to believe that they are esteemed and valued and that they belong to a network of mutual obligations" (Ireys, Chernoff, DeVet & Kim, 2001, p. 772-773). Social support is a concept linked to social relationships that promote health and/or well-being.

Ireys' Social Support Framework

Social support and health can be studied using different approaches from several different perspectives (Hogan et al., 2002). For instance, the sociological tradition has focused on different types of relationships and social integration (Cohen et al., 2001). Another common approach has been the interpersonal tradition. This social support tradition has frameworks that focused on either dyadic or group context (Cohen et al., 2001). Ireys' framework falls under another social support approach that focuses on interventions using one-to-one mentoring. This model was chosen because it provided precise outcome measurements that can be linked with interventions that provide social support to parents of children with Type 1 diabetes mellitus (T1DM).

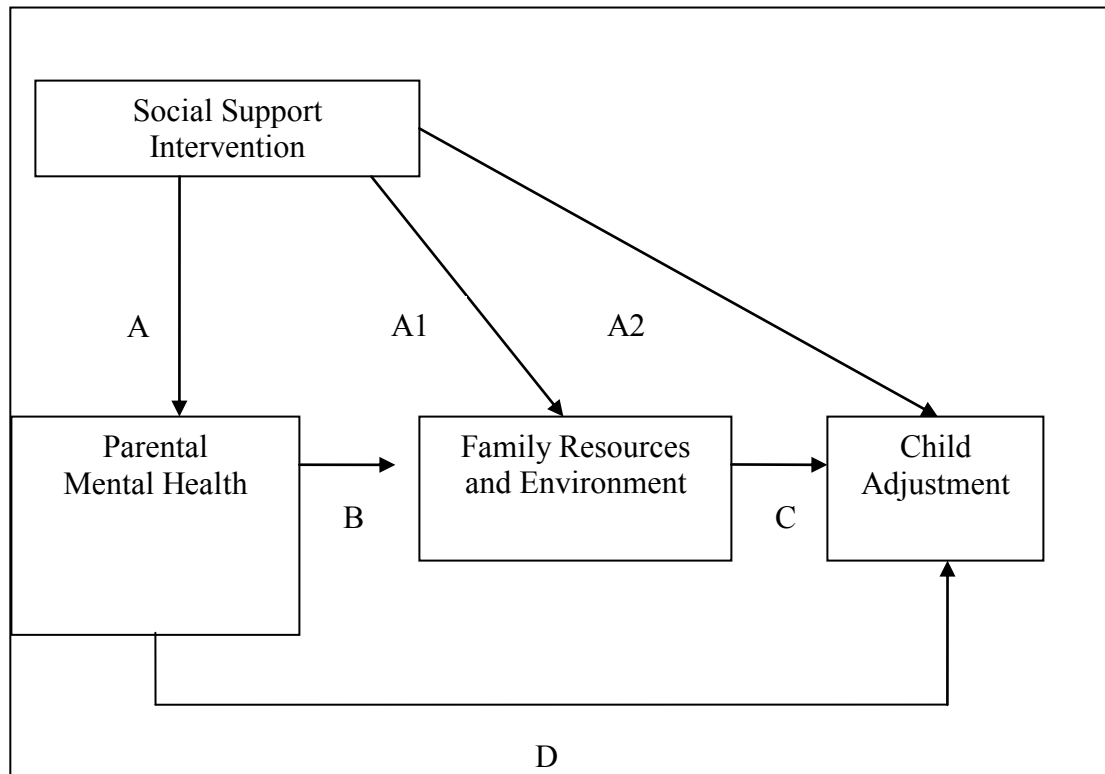
Ireys' overarching framework (Figure 1) illustrates how social support as a resource can directly affect mental health of parents (Path A) raising children with a chronic condition, and depending on how the support intervention is designed, can shape both the family's social and psychological environment and access to resources (Path A1), and directly affect the child's adjustment (Path A2). The parents' mental health can also shape the family environment (Path B) and can influence family members' perceptions of the illness effect on family life, which in turn, can influence the child's adjustment. Parent mental health by itself (Path D) or in combination with family environment (Path C) can also have an effect on the child's (with chronic condition) physical and emotional health, including his/her adjustment to the illness (Ireys, Chernoff, Stein, DeVet & Silver, 2001). The framework supports the hypotheses that by enhancing parental social support, one can lessen parental concern, worry, distress and strain, increase parental confidence, and affect their perception of the impact the chronic illness has on the family, as well as potentially having a direct and indirect effect on child adjustment (Ireys, Chernoff, Stein, DeVet & Silver, 2001).

Enhanced social support may also affect the parents' perception of the impact of the chronic illness on the family and may have a direct or indirect effect on child adjustment. Ireys' conceptual model was built on empirical evidence from a randomized control trial (RCT) involving parents of children with juvenile rheumatoid arthritis (Ireys, Sills, Kolodner, & Walsh, 1996). These parents were matched with veteran parent mentors who provided support for 15 months. This intervention was not administered in the early period after diagnosis (Ireys et al., 1996).

Ireys' social support framework was used to undergird both the parent intervention study, the Social Support to Empower Parents (STEP) intervention (Sullivan-Bolyai et al., 2010) study

and the dissertation itself, a proposed mixed methods descriptive study. The social support framework intervention was provided by parent mentors raising children diagnosed with the same chronic illness as the study participants. In this context, social support was defined in the parent STEP study as providing information that allows individuals to perceive that they are valued and respected. Enhancing parental support affects parental mental health (A), and indirectly affects child adjustment (C, D). Therefore, a social support intervention may also affect the family environment, child or both (Ireys, Chernoff, Stein, et al., 2001).

Figure 1. Overarching Framework for Family-to-Family Social Support Model



In Ireys' model, practical/informational social support is defined as practical tips, referral sources for new services, contact information, and strategies on how to navigate the system (Ireys, Chernoff, Stein, et al., 2001). This type of support is often referred to as "tricks of the trade." The availability of community resources or support groups, contact with schoolteachers

and nurses, and acquisition of supplies are areas where knowledgeable parents can share their personal experiences. These day-to-day management strategies are considered informational support (Ireys, Chernoff, Stein, et al., 2001).

Affirmational social support is defined as verbal and/or nonverbal messages that can increase a parent's confidence in responding to challenges. Verbal affirmational support can be validation of feelings, acknowledging that the parent's emotional experience is normal. Increasing parental confidence through affirmational support allows parents to feel that they can safely care for their newly diagnosed children. Emotional social support is defined as a sense that someone is available to respond and/or to listen to one's concerns (Ireys, Chernoff, Stein, et al., 2001). Continued interest in the parent's viewpoint and the desire to understand the parent's feelings and experiences characterize the definition of emotional support. These definitions of social support types are instrumental to Ireys' framework.

This model has been used as a conceptual framework for many parental peer social support intervention studies that focused on children with chronic health conditions and illnesses (Ainbinder et al., 1998; Chernoff et al., 2002; Ireys, Chernoff, DeVet, & Kim, 2001; Ireys et al., 1996; Nicholas & Keilty, 2007; Sullivan-Bolyai et al., 2004; Symon, 2005). These intervention studies included parents of children with juvenile rheumatoid arthritis, autism, and T1DM. For example, a "family-to-family network" was provided in a randomized intervention for 161 parents of children with asthma, sickle cell anemia, cystic fibrosis, and T1DM (Ireys, Chernoff, Stein, et al., 2001). The studies using Ireys' framework (based on the normative model of support networks) found it useful to structure the parent-to-parent interventions.

Parent-to-parent support programs have become an important part of the service system for children with chronic health conditions. Despite this growth, few empirical studies have

examined the process or outcomes of these support interventions. The authors (Ireys et al., 2001) reviewed results of 3 RCTs of community-based support programs for parents of children with chronic illnesses. The 12-to15-month programs provided informational, affirmational, and emotional support to mothers of school-aged children with chronic illnesses. Support was provided by trained “veterans” (mothers who were raising or had raised children with similar conditions). Results indicated that each program reduced anxiety in high-risk mothers assigned to the experimental group compared to their counterparts in the control group. Results were discussed in terms of “lessons learned” for research, practice and policy, underscoring the benefits of such parent-focused support interventions.

Using Ireys et al.’s seminal work, a feasibility RCT intervention (HOMEWARD) was developed for parents of children newly diagnosed with T1DM, the definitions for social support and the Ireys’ parent support curriculum were used in an effort to reduce parental concern, stress, and anxiety (Sullivan-Bolyai et al., 2004). Building on HOMEWARD, the STEP intervention (Sullivan-Bolyai et al., 2010) used Ireys’ framework as well. As in HOMEWARD, STEP consisted of parent mentor home visits, phone calls, and emails providing practical/informational, affirmational, and emotional support.

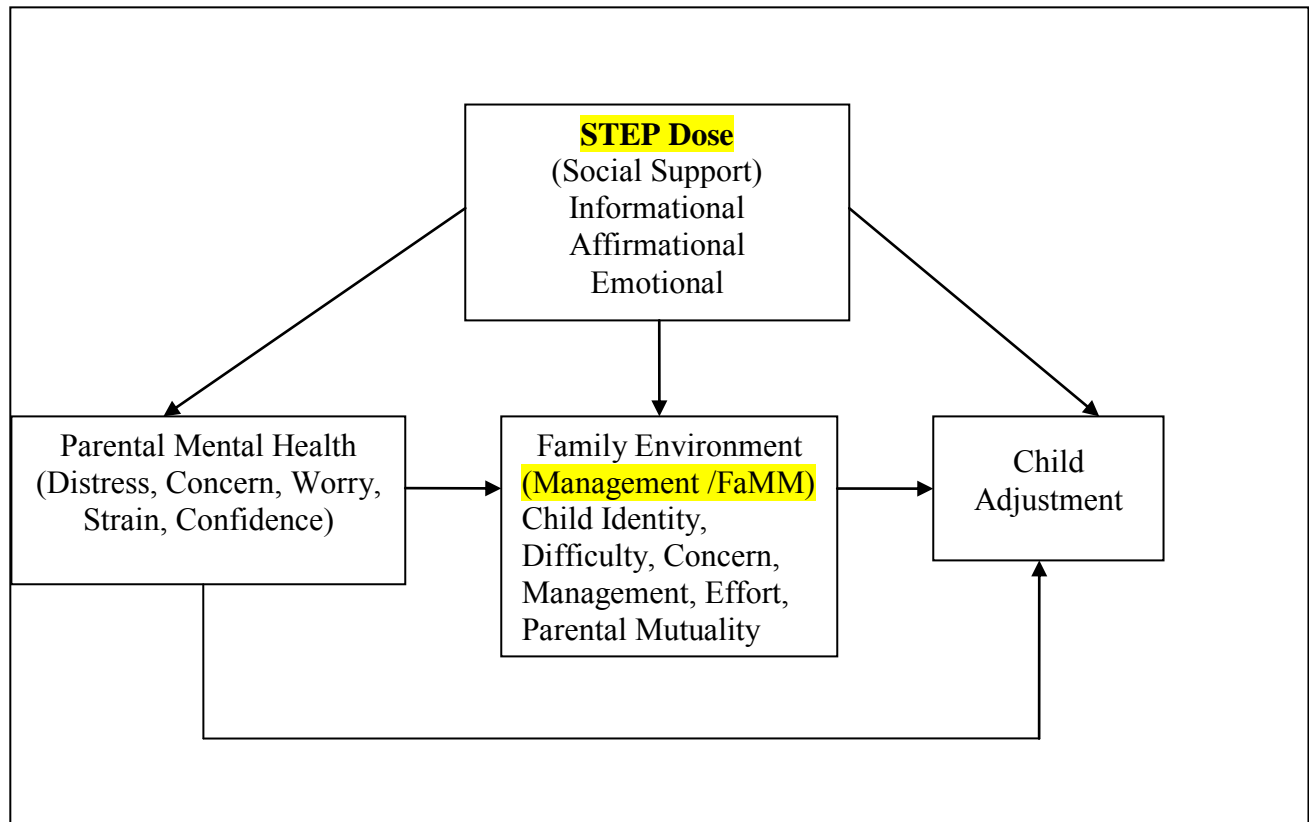
Family Management

Embedded in the family environment construct of Ireys’ framework is the concept of family management. Knafl and Deatrick (1990) described family management as how the family as a unit responded to a childhood chronic illness. The emphasis of family management is on the family responding as a unit and the active, behavioral component of the response (Knafl & Deatrick, 2006). The behaviors are described as “discrete, behavioral accommodations” (Knafl et al., 1996, p.316) that family members use to manage day-to-day, family management in

chronic illness including the themes of parenting philosophy, management mindset and management approach (Knafl et al., 1996). The impact of behaviors and responses of the family unit to a child with a chronic illness defines family management. How a family manages a child's chronic illness contributes to the family environment construct of Ireys' framework, thus having an effect on the child's physical and emotional health.

To review, family management is defined as the process of the family's adaptation to a family member's illness (Knafl & Gilliss, 2002). Family management styles are defined as the different types of family responses to childhood chronic illness (Knafl et al., 1996). One method to describe day-to-day management styles of families with children with chronic illness is the Family Management Style (FMS) Framework, developed through qualitative research and conceptual reviews (Gallo & Knafl, 1998; Knafl & Deatrick, 1990; Knafl & Deatrick, 2003). The FMS was used to develop the Family Management Measurement (FaMM), which quantifies how families manage caring for a child with a chronic condition or illness and the extent to which they incorporate condition management into everyday family life (Knafl et al., 2009). For the proposed study, the FaMM has been added to Ireys' framework (Figure 2) as another measure of day-to-day management of the family environment. Child identity, difficulty, concern, management, and effort were measured as aspects of family environment.

Figure 2. Ireys' Social Support Framework Modified for the Proposed Study



Summary

Approximately 13,000 children in the United States are being diagnosed annually with Type 1 diabetes (CDC, 2009). A family's response to a child's diagnosis of chronic illness must address the treatment regimen and how this is incorporated into everyday life (Knafl & Deatrick, 2003). Providing opportunities for parental peer social support in the population with this life-changing diagnosis may enhance adjustment, physical, emotional, and family outcomes. Describing parents' day-to-day management of chronic illness may enable peer social support interventions to be more precisely individualized. The study was guided by an adaptation of Ireys' social support framework.

Purpose Statement and Aims

The purpose of this mixed-methods descriptive study was to explore parents' experiences with social support following the STEP intervention and to examine the usefulness of the Family Management Measure (FaMM) in this population. The specific aims of this study were to:

- 1) Describe parents' experiences with STEP social support intervention,
- 2) Describe parents' day-to-day diabetes management as measured by the Family Management Measure (FaMM) (six dimensions: child's daily life, condition management ability, condition management effort, family life difficulty, parental mutuality, and view of condition impact),
- 3) Describe the relationship between parental management scores in the six FaMM dimensions and the intervention dose used,
- 4) Explore FaMM scores in relationship to parent satisfaction with the STEP social support intervention.

CHAPTER III

METHODS

Introduction

In this chapter I will describe the parent STEP study and, in more detail, the methods for the dissertation study, i.e., its design, sample, setting, data collection, and data analysis. For data collection, I will describe the process completed in the parent study. I will also describe potential difficulties with the analytic process, detail the consideration of human subjects' rights, and summarize the chapter. A brief description of the intervention follows.

This dissertation study was the qualitative portion of the STEP intervention, a randomized controlled trial (RCT). In that study, I worked as a research assistant (RA) and conducted 14 post-intervention interviews with both mothers and fathers randomized to the experimental arm of the intervention. Another 8 interviews were conducted by Dr. Sullivan-Bolyai, the principal investigator (PI) of the study. The purpose of the interviews was to explore parents' experiences related to participating in the intervention. After the interviews I administered a family-focused management scale that measured how parents managed day-to-day care for a child with a chronic illness/condition (FaMM).

STEP Study

The parent study was a RCT conducted over 4 ½ years. After randomization, parents of children with T1DM received either the peer support intervention (support from a trained parent mentor) or a control condition (the telephone number of a knowledgeable parent). The STEP study provided the three types of social support: as described in Chapter II (informational, affirmational, and emotional).

Ten STEP parent mentors were carefully selected by the principal investigator and the diabetes teams at the clinical sites. The parents chosen were knowledgeable in management of T1DM, child development issues and identifying community resources (Sullivan-Bolyai et al., 2010). Additional selection criteria included competence, confidence, flexibility in managing their own child's T1DM, and working well with the diabetes team members. The parent mentors chosen were active listeners, easy to talk to in informal settings and nurturing yet assertive when advocating for their children. The seven mothers and three fathers chosen as mentors each had 1-3 children, one of whom was diagnosed with T1DM (Sullivan-Bolyai et al., 2010). Duration of illness was at least 1 year.

As with HOMEWARD, parent mentor training was provided in the STEP study (Sullivan-Bolyai et al., 2010). The principal investigator and a parent-mentor coordinator trained the parent mentors using the developed social support curriculum. The goals included establishing and maintaining a supportive relationship with each parent participant, helping parents identify and address unmet needs, and helping parents identify and use existing sources of support in their own families and communities (Sullivan-Bolyai, Grey, Deatrick et al., 2004). Seven core topics were discussed by the parent mentors: helping the child grow and develop, caregiver day-to-day management responsibilities, siblings, behavior/discipline, dealing with physicians and the medical system, dealing with daycare or school-related issues, and management of out-of-school activities such as babysitting, camps, and parties (Sullivan-Bolyai, Grey, Deatrick et al., 2004). During the course of the intervention, the parent-mentor supervisor debriefed parent mentors after their parent-to-parent interactions (Sullivan-Bolyai et al., 2010).

For informational support, the STEP parent mentors reinforced management information introduced by the diabetes team during the child's short hospital stay. This information included

effective use of the diabetes team, practical illness-related information, and community resources. The intervention group also received information on how to incorporate day-to-day illness management into family life. Parents in the experimental arm were given opportunities to talk with parent mentors who validated feelings and reassured parents, thus providing affirmational and emotional support. This type of peer support provided positive feedback on and validation of parents' concerns associated with the day-to-day illness-related management of these young children (Sullivan-Bolyai et al., 2010). These participants were parents of children under 12 years old and newly diagnosed with T1DM. At the end of the trial, parents who received the intervention were reconsented and interviewed about their experiences with the STEP intervention. This portion of the study was conducted under the auspices of the author's dissertation.

Dissertation: Mixed Methods Design and Rationale

This dissertation study used a concurrent nested mixed methods design with qualitative inquiry as the core, and a quantitative measure (FaMM) as the nested component. One of the principles of mixed method research is working with as few data sets as possible (Creswell, Clark, Gutmann, & Hanson, 2003). Parents who completed the experimental arm (12 months with access to a parent mentor) of the STEP study were approached via email or telephone by the PI or this author to participate in a post-intervention interview. This select group of parents provided a small, purposive sample. Following the interview, parents completed the FaMM to provide a single supplemental data collection point.

Qualitative description, the research method used as the basis of this proposed mixed methods study, is based in naturalistic inquiry and is used to describe the meaning of the experience in context. It is the least interpretive of the qualitative inquiry methods. Sandelowski

(2000; 2010) states that the goal of qualitative description is to provide a comprehensive summary in everyday terms. In reference to mixed methods, Maxwell and Loomis (2003) discussed the qualitative and quantitative components working well together, emphasizing holistic understanding as well as efficient and successful functioning. The use of a mixed methods approach is discussed in the nursing literature as providing a more balanced perspective, moving towards holism (Morse & Chung, 2003).

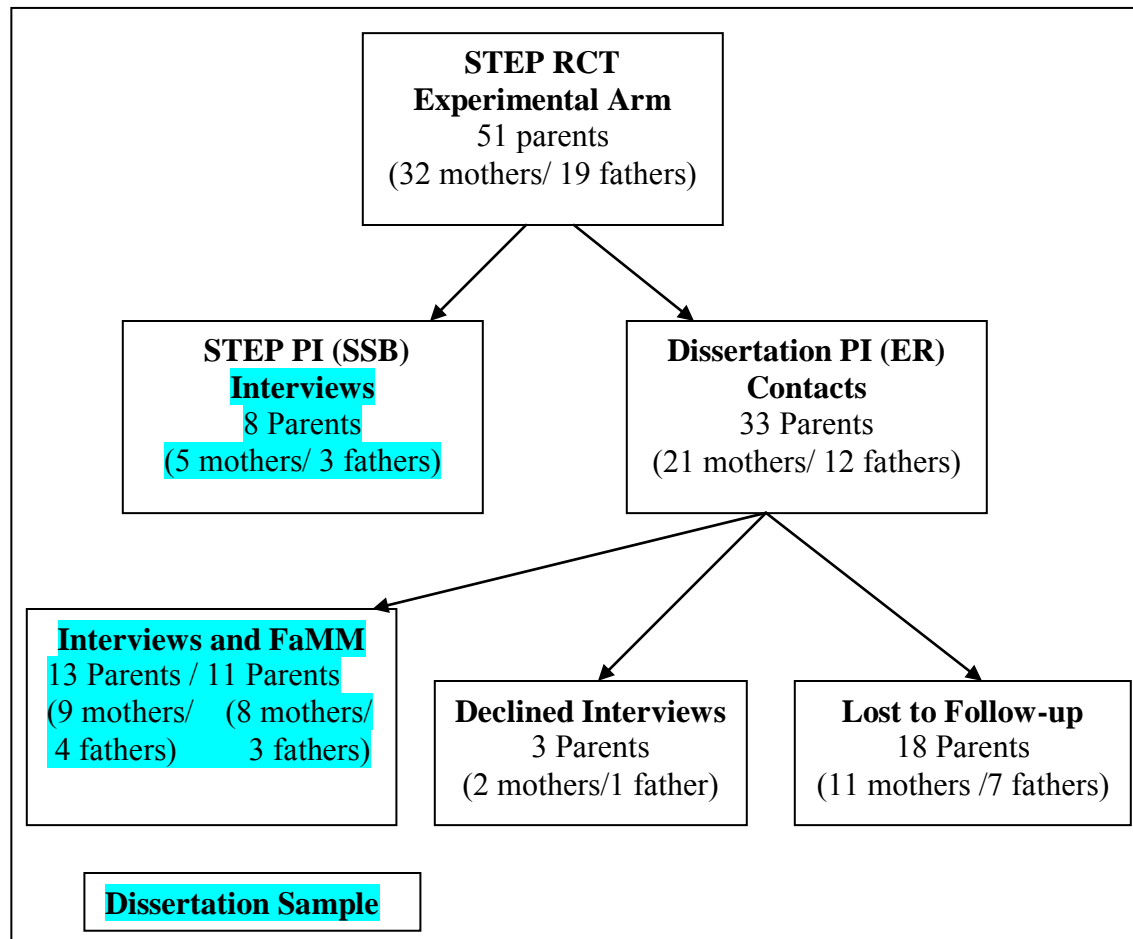
This integrated design also reflects the use of an approach that can provide the integrated knowledge required for nursing practice (Flemming, 2007). By nesting the quantitative method within the qualitative method, the study can ask a different question than that asked in the dominant (qualitative) method (Creswell et al., 2003). To date, no studies have addressed how families manage the care of children with T1DM with regard to child identity, concern, effort, difficulty, and management. In the dissertation study, the supplemental FaMM questionnaire helps describe how this specific group of parents managed their child's chronic condition. The FaMM data may also help individualize what type of social support is most needed.

Collecting data in interviews and with the FaMM is referred to as mixing data collection across methods or intermethod mixing (Johnson & Turner, 2003). Use of these two data collection methods was chosen to enhance understanding of these participants' experiences. Indeed, coupling qualitative with quantitative methods has been found to enhance the illumination of phenomena related to vulnerable families not captured using a single approach (Shepard, Orsi, Mahon, & Carroll, 2002). In the dissertation study, looking at management-specific information captured by the FaMM enriches parents' descriptions of the STEP intervention experience, especially for those who received varying amounts of the intervention (intervention dose).

Sample and Setting

A purposive sample was drawn from the 51 parents (32 mothers and 19 fathers) who participated in the STEP trial and had been randomized to the experimental arm. Of these parents, 8 (6 mothers and 2 fathers) were interviewed by Dr. Sullivan-Bolyai after the intervention. As an RA, I attempted to contact 21 parents in the experimental arm via email or telephone and invited them to participate in post-intervention interviews, which were conducted in the participants' homes whenever possible. One family had moved (without contact information), 2 families (2 mothers and 1 father) declined the post-intervention interview and 11 families did not return emails or telephone calls to this author (see Figure 3). An alternate interview location such as a clinic setting was offered. Those parents who were contacted by the author and declined (n= 3) this interview were asked to share the reason why. This information will be reported in the Results chapter.

Figure 3. Dissertation sample extracted from STEP RCT



Data Collection Procedure

After participants signed a new informed consent (which had been revised to reflect the inclusion of the FaMM) they were interviewed face-to-face using the STEP interview guide developed by the PI (Table 1). All interviews were audiotaped. The interviews and data collection process lasted approximately 30- 90 minutes. Field notes were made to document observations of nonverbal expressions and actions. The audiotapes were transcribed verbatim by a professional transcriptionist and stored in a locked file in the PI's office.

At the completion of the interviews, participants were asked to complete a paper copy of the FaMM (self-report), which was checked for any missing data. While participants completed the FaMM, I was present to answer any questions about item wording or procedures.

Table 1

STEP Interview Guide

Aim/ Concept	Question	Probe
Aim 1 Describe mothers' and fathers' experiences with the parental support intervention - STEP	1) Can you share with me how you came to know your child had diabetes? 2) Since the focus of the study was social support, can you tell me what it means to you, how do you describe it? 3) Can you share with me a little about the experience of interacting with the parent mentor (PM)? 4) How many times has the parent mentor made home visits? 5) How often was telephone contact made with the parent mentor? 6) Were the number and timing of the visits and calls appropriate? 9) What topics did you and the parent mentor discuss? 10) What other topics would you recommend they discuss?	At what point after diagnosis were you contacted by the PM? Was it more often at first? Did you feel comfortable calling them? Did they call you routinely?
Aim 4 Explore FaMM scores in relationship to parent satisfaction with the STEP social support intervention	7) Can you tell me what was helpful about the program? What was not helpful? 8) On a scale of 1-5 – (5 being the most helpful), how helpful was it? 11) What are your recommendations for how we might improve the program to meet your own specific needs?	Was it too much, too little, just right? What are some things the parent mentor could have done differently?

*Measures**Qualitative measure*

Qualitative data were gathered from parents in interviews following their 12-month participation in the experimental arm of STEP study. Interview questions (Appendix A) were developed by Dr. Sullivan-Bolyai. Interviews were guided by questions and probes in the interview guide (Table 1).

Quantitative measures

Quantitative measures included parents' demographic information and their perceptions of family management of their child's treatment and incorporation of management into everyday life. Demographic data (race, educational level, marital status, number of children in the family, number of adults caring for the child with T1DM, and birth order of the child with T1DM) were collected during the recruitment process for the STEP study. Following the interviews, quantitative data on parents' perceptions of family management were collected with the Family Management Measure (FaMM) (Appendix B). The FaMM is a recently developed and tested instrument. The potential application of the FaMM to Australian families with a chronically ill child is currently being assessed for cultural appropriateness (Wiegand & Deatrick, 2009). Although families with children with T1DM were among the families tested to develop the FaMM, no published research to date has used the FaMM exclusively in families with children under 12 years old and newly diagnosed with T1DM.

The FaMM was developed using the Family Management Style Framework (Knafl, Deatrick, & Gallo, 2008; Knafl et al., 2007). The instrument measures parents' perceptions of family management of caring for a child with a chronic illness/condition and the extent to which

they incorporate the management into everyday family life. The FaMM also measures key aspects that may impede or support optimal child and family functioning (Knafl et al., 2008).

The 53-item FaMM has two sections: Section 1 has 45 items measured in five dimensions (scales) and Section 2 has 8 items measured in one dimension (scale). Section 1 items are answered by all parents (whether partnered or not) and comprise five summated scales: Child Identity, Concern, Difficulty, Effort, and Manageability. Each item has five response options 1 (strongly disagree) to 5 (strongly agree). *Child Identity* (5 items) reflects parents' perceptions of their child and his/her everyday life. *Concern* (10 items) reflects parents' perceptions of the seriousness of the condition and its implications for their child's and their family's future. The focus of concern is apprehension about the future. *Difficulty* (14 items) addresses parents' perceptions of the extent to which having a child with a chronic condition makes family life difficult. *Effort* (4 items) addresses the time and work needed to manage the condition. *Manageability* (12 items) addresses parents' perceptions of the overall manageability of the child's condition, including knowing what needs to be done to take care of the condition and their ability to competently manage their child's condition (Knafl et al., 2008).

The items in Section 2 are answered only by parents with adult partners in the household and measure a sixth summated scale: Parental Mutuality. *Parental Mutuality* (8 items) addresses parents' perceptions of support, shared views, and satisfaction with how the partners work together to manage the child's condition (Knafl et al., 2008).

Internal consistency reliability.

Internal consistency reliability refers to the homogeneity of items within a scale (Waltz, Stickland, & Lenz, 2005). Knafl et al. (2009) assessed psychometric properties of the FaMM with a sample of 579 parents of children aged 3 to 19 with chronic conditions. The internal consistency reliability for the FaMM scales (Table 2), adjusted for inter-parental correlation, ranged from .72 to .90 for mothers and .73 to .91 for fathers (Knafl et al., 2009). These results are above 0.7, which indicates acceptable reliability, and >0.8, indicating good reliability (Waltz et al., 2005).

The test-retest reliability measures the stability of a scale over a specific period (DeVellis, 2003; Waltz et al., 2005). The 2- to 4-week test-retest reliability, based on responses from 65 parents and adjusted for inter-parental correlation, ranged from .71 to .94 (Knafl et al., 2009).

Table 2

Internal Consistency Reliability of the FaMM Scales for Mothers and Fathers

Scale	Mothers	Fathers
Child's Daily Life(5 items)	.76	.79
Condition Management Ability (12 items)	.72	.73
Condition Management Effort (4 items)	.74	.78
Family Life Difficulty (14 items)	.90	.91
Parental Mutuality (8 items)	.79	.75
View of Condition Impact (10 items)	.73	.77

Adapted from Knafl et al. (2009)

Construct validity

Construct validity reflects the degree to which an instrument accurately measures the theoretical concept it was designed to assess (Waltz et al., 2005). The construct validity of the FaMM scales was assessed by testing whether scores on various scales correlated with scores on established measures of the same theoretical constructs (Knafl et al., 2009). Specifically, FaMM

scores for child identity, concern, difficulty, effort, manageability, and parental mutuality were correlated with established measures of family functioning (the Family Assessment Device) child functional status (Eyberg Child Behavior Inventory), and child behavior (Functional Status Measure-II [FSM-II]). Construct validity of the FaMM was supported by significant correlations ($p < .01$) of weak to moderate strength between each scale and its related measure, with directions of relationships as expected (Table 3). Construct validity was demonstrated by the significant relationships in hypothesized directions between the six FaMM scales and the established measures (Knafl et al., 2009).

To ensure against social desirability bias in completing the FaMM, the authors tested the hypothesis that scores on all FaMM scales would have nonsignificant relationships with scores on Marlowe-Crowne Social Desirability measure (Knafl et al., 2009). The authors acknowledged that there were limitations to this psychometric assessment of the FaMM, including the sample lacking single mothers, culturally diverse parents, and limited geographic location (Knafl et al., 2009).

Table 3

Composite Construct Validity Correlations of FaMM Scales

FaMM Scale	FAD Negative Family Functioning	FSM-II Positive Child Functional Status	ECBI Intensity Negative Total Child adaptation	ECBI Problem Problematic Child Adaptation	Marlowe- Crowne Social Desirability
Child's Daily Life	-0.21*	0.39*	-0.22*	-0.21*	0.05
Condition Management	-0.35*	0.32*	-0.25*	-0.23*	0.04
Ability Condition Management	0.16*	-0.33*	0.17*	0.13*	-0.05
Family Life Difficulty	0.38*	-0.45*	0.33*	0.31*	-0.07
Parental Mutuality	-0.64*	0.20*	-0.28*	-0.25*	0.11*
View of Condition Impact	0.22*	-0.32*	0.15*	0.09*	<0.01

Note. FAD: Family Assessment Device; FSM-II: Functional Status Measure II; ECBI: Eyberg Child Behavior Inventory. * $p < .01$; all other correlations $> .10$

Adapted from Knafl et al., 2009

Data Management

Appropriate data management is critical prior to data analysis in qualitative description (Knafl & Webster, 1988). Qualitative data management consists of professional transcription of interviews, cross checking the transcriptions with audiotapes, and incorporating observations, field notes, procedural and personal reflections and insights into each interview document (Knafl & Webster, 1988)

Data were managed and analyzed as described in Table 4. Transcripts were entered into NVivo software and checked against audiotapes for accuracy and tone. Field notes were incorporated into NVivo. Scores on FaMM scales were calculated per the scoring instructions (Appendix C) and entered into SPSS version 17, assessed for missing data, and all identifying

information removed. No data were missing from the FaMM instruments. The demographics and intervention dose (measured in total minutes of contact with the parent mentor) has been entered into the main data set. This data were copied and placed in a unique SPSS folder.

Table 4

Data Management and Analysis

Aim	Data Management	Data Analysis
<u>Aim 1</u> Describe mothers' and fathers' experiences with the peer support intervention-STEP	A. Enter transcripts into NVivo Software. B. Check all transcripts against audiotapes for accuracy and tone C. Incorporate field notes	A. Qualitative content analysis of transcripts: summarize each transcript, code topic data, identify (within and across comparisons) common themes and subthemes; variations. B. Cluster and separate to see commonalities and differences in themes and subthemes between mother/father dyads and mothers only
<u>Aim 2</u> Describe parents' day-to-day diabetes management as measured by the six FaMM dimensions	A. Enter data into SPSS version 17 B. Assess data for missing information C. De-identify data	A. Generate basic descriptive statistics (mean, median, frequency) for each of the six FaMM dimensions B. Run Cronbach's Alpha for each of the six FaMM dimensions C. Cluster mother/father dyad data D. Generate descriptive statistics for demographic data
<u>Aim 3</u> Describe the relationship between parental management scores in the 6 FaMM dimensions and intervention dose used.	A. Enter intervention dose for each parent into the main data set B. Enter score for each of the 6 FaMM dimensions	A. Describe the six FaMM dimensions in relationship to the intervention dose (Matrix).
<u>Aim 4</u> Explore FaMM scores in relationship to parent satisfaction with the STEP intervention	A. For only parents who completed the FaMM and conveyed a 1-5 level of satisfaction with the STEP intervention.	A. Describe the six FaMM dimension scores in relationship to satisfaction scores with the STEP intervention

*Data Analysis**Qualitative Data*

Qualitative description provided the research design to describe the individuals' experiences with the STEP intervention in their own words. Qualitative content analysis (Miles & Huberman, 1994) was used to examine the data. The goal of qualitative analysis is to extract meaning from the data and present results in a way to convince the reader of credibility. Qualitative content analysis uses a systematic format to develop codes or labels to describe data from careful reading of the transcripts (Miles & Huberman, 1994; Richards & Morse, 2007). The purpose of coding data is to cluster larger pieces of data into a smaller number of focused, descriptive themes (Miles & Huberman, 1994).

Each interview was transcribed by a professional transcriptionist. Transcripts were imported into NVivo. Each transcript was read and each interview audiotape reviewed, checked for accuracy and tone, corrections made as needed. Field notes and personal reflections were incorporated into the transcript after importing it into NVivo. A summary was written for each interview, and then analyzed by qualitative content analysis (Creswell, 2007).

Qualitative content analysis begins with coding sections of data. The Ireys' social support framework was used to help develop the interview guide. During the coding process, new ideas or concepts, not related to Ireys' framework, were allowed to emerge. Per Miles and Huberman (1994), as coding began, data were sorted to identify similar phrases, themes, patterns and sequences of statements. As data coding progressed and categories developed, they were constructed or rebuilt into themes. Common themes, variations and differences were identified and compared within and across each transcript (Ayres, Kavanaugh, & Knafl, 2003). Personal

notes about the data coding were noted as attachments in NVivo. The end result is a representation of the data.

Quantitative Data

Parents' demographic data were analyzed by descriptive statistics. The scores for each of the FaMM's six scales were calculated per the FaMM's scoring instructions (Knafl et al., 2009). The resulting scores for each scale (child's daily life, condition management ability, condition management effort, family life difficulty, parental mutuality and view of condition impact) were analyzed and reported by basic descriptive statistics (mean, median, frequency). Intervention dose was determined by the total number of contact minutes that each parent had with the parent mentor. Satisfaction scores (ranging 1-5 with 1= least satisfied and 5= highly satisfied) and intervention doses were analyzed and compared within and across transcript summaries. Individual intervention dose was compared with interview comments regarding overall conveyed satisfaction with the STEP program. The FaMM scores for each scale were compared and contrasted with the 1-5 level of satisfaction scores. Overall conveyed satisfaction from transcript summaries was compared with satisfaction scores.

The parents who completed the post-intervention interview were compared with the parents who did not complete the interview by demographic data (race, educational level, marital status, number of children in the family, number of adults caring for the child with T1DM, and birth order of the child with T1DM) to determine any differences.

The qualitative data collected in interviews and the quantitative data collected with the FaMM and satisfaction scale were analyzed in parallel. The two types of data were matched by subject. In addition to the themes identified in analyzing the interviews, specifics were reviewed

to glean more information if required. The parallel mixed analysis occurred by independently analyzing the data, then comparing and consolidating them.

Trustworthiness of Qualitative Data

Trustworthiness of qualitative data corresponds to the concepts of reliability and validity in quantitative research (Lincoln & Guba, 1985). In response to this, efforts were made to formalize the concept of trustworthiness of the qualitative study. Trustworthiness refers to the truth value, applicability, and consistency of qualitative data (Lincoln & Guba, 1985). Truth value is often considered the “credibility of the inquiry,” applicability the “transferability of the results,” and consistency the “dependability of the results” (Morse & Richards, 2002, p. 168).

Truth value indicates the credibility of the representation of the qualitative data (each participant’s constructed reality). These representations or reconstructions from a qualitative study should be approved by the participants as constructors of the multiple realities (Lincoln & Guba, 1985). Applicability in qualitative research refers to the ability to transfer results from one study to another setting or population. The ability to apply the results of a specific study does not rely upon the original investigator, but with another investigator who seeks to apply the results (Lincoln & Guba, 1985). The original investigator is only responsible for providing as much data as possible to assist subsequent investigators to judge potential application to other populations or settings. Consistency is a difficult concept in qualitative research as replication may not always be achievable. The four components commonly used to maintain trustworthiness of qualitative data are credibility, transferability, dependability, and confirmability.

Credibility

Strategies to increase the probability of producing credible findings and used in this study include prolonged engagement, persistent observation, triangulation, peer debriefing, and

member checking (Lincoln & Guba, 1985). Prolonged engagement with study participants increases the opportunity to gather rich, descriptive data. Engagement in this study was achieved during face-to-face interviews. Persistent observation of participants may lead the investigator to determine essential information (Lincoln & Guba, 1985). Participants were consistently observed during the face-to-face interview process and completion of the FaMM.

Triangulation involves applying and combining several research methodologies to study the same phenomenon (Lincoln & Guba, 1985). Triangulation can occur by using different methods or collecting data from different participants who restate crucial points of interest. Triangulation was achieved in the proposed study by using qualitative data from the interviews and quantitative data from the FaMM. Credibility of the qualitative data was obtained by reviewing themes that emerge from the data analysis and review of field notes as well as by two researchers (the PI and I) coding the same interview excerpts and comparing findings for interrater reliability.

Lincoln and Guba's (1985) third technique is a peer debriefing process in which an external check is performed. During the course of the inquiry, the researcher avails him or herself on a regular basis to meet with a peer. This peer is able to ask the researcher exploring questions, listen to the testing of hypotheses, enhance the search for the emerging research design, and provide opportunity for catharsis (Lincoln & Guba, 1985). I have used the PI as a peer debriefer throughout this dissertation study.

The final strategy of assuring credibility in this study was member checks (Lincoln & Guba, 1985). The most crucial technique for establishing credibility, member checking involves discussing the findings and conclusions with the study participants who provided the data. Testing the researcher's conclusions is essential to qualitative inquiry. Member checks can be

performed both formally and informally. Informal checking occurs during the interviews themselves while more formal checking may take place in a focus group or individually after the researcher has re-presented the data in written form. I performed informal member checks during the interview with the interviewees. A formal member check was initiated once themes and subthemes were identified.

Transferability

As discussed above, the second criterion for trustworthiness of qualitative findings, transferability is ultimately the responsibility of the investigator who wishes to apply the results. To enhance transferability, the original researcher has the responsibility to provide a thick description of the data, thus helping other researchers reach conclusions regarding the possibility of transferring results (Lincoln & Guba, 1985). This researcher provided a rich description of data by including subjects' verbatim comments into the summaries of their experiences.

Dependability and Confirmability

Both dependability and confirmability can be assured by four techniques: keeping an audit trail, establishing a specific audit process, triangulation and reflexivity. The audit trail consists of items the researcher maintains and archives during the study. The interview audiotapes, transcripts and FaMM data were maintained in the PI's office in locked cabinets until data analysis commenced and then were maintained in locked cabinets of this researcher. Products of data synthesis and process notes were maintained with the PI.

A technique to enhance confirmability is the researcher's personal reflexive journal (Lincoln & Guba, 1985). This journal provides information about the human instrument (the researcher) that in quantitative inquiry may be reported about the instruments used in those studies. Daily entries are desirable. Finlay (2002) refers to this method as the researcher

engaging in an explicit, self-aware meta-analysis of the research process. I used a reflective journal to record impressions following each of the interview sessions. Field notes were entered into the imported transcripts. Reflexivity is also a reflection of what the researcher brings to the study, and may arise during the data analysis. I have worked with families with children with chronic illnesses before, but not those with children newly diagnosed with T1DM. The researcher utilized the above techniques as each fits the research design to ensure rigor in qualitative inquiry. Importance of trustworthiness in a qualitative study as discussed above is the equivalent to validity and reliability in quantitative research.

The research design and type of methodology determines the appropriate techniques for assuring credibility. The application of techniques that increase the trustworthiness of the data assisted in summarizing the data and providing a “truer” picture of the participants’ experiences. In the qualitative descriptive portion of this mixed methods study, the elements of trustworthiness – truth value, applicability and consistency were maintained by debriefing, member checking, and reflexive journaling.

Protection of Human Subjects and Ethical Considerations

The STEP intervention study was approved by the Institutional Review Board (IRB) of the University of Massachusetts, Worcester. All study subjects during the intervention phase had signed informed consent prior to entering the study. Before interviewing participants, I was added to the PI’s IRB protocols. Informed consent is viewed as an ongoing process. Study participants must, when appropriate, be provided with the opportunity to re-consent for continued participation in a study (U.S. Department of Health and Human Services [USDHHS], 2007). This policy states that if the protocol design has changed, study participants should be requested to re-consent (USDHHS, 2007). Longitudinal studies over 6 months' duration also

require re-consent. Since the intervention trial was 12 months long, participants were asked to re-consent. In addition, the STEP protocol had changed by adding the FaMM to gather supplemental data. Prior to the post-intervention interviews, parents were again asked to sign informed consents specifically for the interview and completion of the FaMM. When interviews were conducted, I wore appropriate photo identification as a PhD student and provided contact information for the program advisor if needed.

Issues related to protection of human subjects during the interview process included confidentiality, privacy, and full disclosure of the interview purpose and methods. Human subjects were further protected by obtaining parents' written consent before the interviews and by providing a private interview in a location of the participant's choosing. Prior to beginning the interview, parents were told they could stop the interview at any time. All interviews were conducted in the privacy of the families' homes, except for one interview that was conducted at the parent's request in a public library. If subjects had become upset or requested professional advice from me, they would have been referred to the PI. However, this situation did not occur during data collection.

All information (interviews, questionnaires, identifying information) was de-identified and secured during the data collection process. Currently, all data are secured in a locked drawer in the PI's private office. During the data management and analysis processes, confidentiality was maintained by storing the deidentified data and the code book that identifies participants by name in locked cabinets in the PI's office and by limiting access to the study information to only the committee chair (PI), other committee members, and me.

Summary

This chapter summarized the design and methods for the dissertation research, which is part of an intervention study that provided peer social support to parents of young children newly diagnosed with T1DM. The dissertation research included the qualitative portion of the intervention study. The design was a concurrent nested mixed methods study with qualitative inquiry as the core (post-intervention interviews) and quantitative inquiry (FaMM) as the nested component. The dissertation study was undergirded by Ireys' Social Support Framework, which also guided the parent intervention study. Qualitative data were gathered during the 12-month exit interview for the STEP intervention study. At the same time, quantitative data were collected with the FaMM, a relatively new research instrument. The combination of data gained from the proposed study may further describe how the intervention supported the parents during a stressful time in their family life. The data may also help describe how to best individualize parent support according to specific family management behaviors used in raising children with T1DM.

Chapter IV

Results

A mixed method approach with qualitative descriptive methodology as the prime source was used to study the experience of parents involved in the experimental arm of the Social Support to Empower Parents (STEP) randomized control trial (RCT) study, a social support intervention for parents of children newly diagnosed with Type 1 diabetes mellitus (T1DM). These parents had completed the 12-month intervention provided by a trained parent mentor. The addition of the Family Management Measure (FaMM) provided quantitative data regarding family adaptation to the diagnosis of this chronic illness. Sample characteristics, a description of themes identified in the qualitative analysis with illustrative participant quotes, and descriptive statistics from the FaMM follow. The results are organized by study aim. Result for aims 3 and 4 will be presented in an integrated manner.

Participants

Demographic data were collected in the STEP RCT. A total of 21 parents (14 mothers and 7 fathers) provided qualitative data through one-time interviews at the conclusion of the 12-month intervention. Fourteen families were represented in the sample. Eight interviews (5 mothers and 3 fathers) were conducted by the principal investigator of the STEP RCT via telephone. The remaining 13 face-to-face interviews (9 mothers and 4 fathers) were conducted by this investigator. Three parent dyads, each consisting of one mother and one father were interviewed and completed the FaMM. These interviews took place in the parents' homes ($n=12$) or in a public library at the participant's request ($n=1$) from October 2007 through October 2008. All interviews were audiotaped. The face-to-face interviews and data collection process lasted approximately 30-90 minutes. Following the interviews, 11 of the 13 parents interviewed

by this investigator completed the FaMM instrument. Additional attempts were made to contact other parents who had participated in the intervention arm of the STEP RCT. Due to a lack of response to this investigator's attempted contact or parent contact indicating no interest in the post-intervention interview, recruitment was completed.

All statistics were run using SPSS 17.0. Frequencies were run, with some data missing (Table 5). Of the 21 parents, 33 % ($n=7$) were male and 67 % female ($n=14$). Parents' ages ranged from 22 to 43 years; the mean age was 36 years (SD 5 years; Mdn 37 years). All of the parents were heterosexual married couples and had two parents in the home. The majority of parents identified themselves as white ($n=17$; 85%) while 15% ($n=3$) identified as Latino. Fifty percent of parents ($n=10$) were working part or full time while the remaining parents were not working outside the home. Most of the parents reported having a post-secondary education ($n=12$, 75%). Demographic characteristics are contained in Table 5.

Table 5
Baseline Demographics

	Parents Interviewed (<i>n</i> = 21)		Parents Completed FaMM (<i>n</i> = 11)	
Variable	<i>n</i>	%	<i>n</i>	%
Gender				
Female	14	67	8	73
Male	7	33	3	27
Race				
White	17	85	8	80
Latino	3	15	2	20
Missing	1	.05	1	
Age (years)				
22-25	1	5	1	10
26-30	1	5	1	10
31-35	7	35	3	30
36-40	7	35	1	10
41-45	4	20	4	40
Missing	1	.05	1	
Parent Education				
≤ High School	4	25	1	17
Some College	3	19	1	17
≥ College Degree	9	56	4	66
Missing	5	24	5	
Marital Status				
Married	20	100	10	100
Missing	1	.05	1	

Aim 1: Describe mothers’ and fathers’ experiences with the peer support intervention: STEP RCT.

Major Themes

A qualitative descriptive approach was used to study the subjective experience of parents’ involvement with the STEP RCT intervention. The necessity to adapt to a child’s diagnosis and associated care was a constant. One mother emphasized: “Going home with a child newly diagnosed is tougher than going home with a newborn!” When asked about the topics discussed with parent mentors, parents’ responses often began with “anything and everything.” No

difference was noted between the themes identified between interviewed mother/father dyads and mothers only.

Parents were involved in telephone, email, and/or face-to-face contact with parent mentors. Many parents reported appreciation of the face-to-face contact to meet parent mentors in person; the telephone contacts were reported to be convenient for all but one parent, who stated that at times she found the parent mentor telephone calls coming at busy times and preferred contact via email. One mother stated the email contact was a good option as she could quickly write an email question as she was thinking about it. An email question would not need an immediate response that a telephone call to the parent mentor might suggest.

Parents who had an increased amount of parent mentor contact described a level of comfort with contacting the parent mentor, family visits, and development of on-going friendships. Parents with fewer parent mentor contacts described asking the questions (and getting the answers) they felt were important, yet still being able to contact the parent mentor if needed.

Three major themes emerged from the parents' responses regarding their experience with the STEP parent mentors: *availability*, *practical tips*, and *common ground*. These themes were present in all interviews, both mother/father dyads and mothers only. All parents interviewed referred to the parent mentors as readily available to answer questions and listen to concerns, as reliable resources for practical tips, and as those "who had been there" and knew what they were experiencing. When asked what social support meant to her, one mother stated: "It's just having someone to talk to who's been there, knows what you're going through." Following is a rich description of each of the identified themes.

Availability

Parent mentor *availability* was identified as the first major theme. Parents discussed, at length, the comfort of knowing the parent mentors were available for them at any time. All parents indicated that the parent mentors conveyed the idea to call them at anytime – “just give a call.” Having a veteran parent to contact was emphasized by many parents as the most important piece of the STEP intervention. Parents expressed that “having someone to talk to” made stressful situations more bearable. Parents reported feeling comfortable that they could call the parent mentor at any time for advice and support, not needing to contact medical or nursing professionals for every question. Different methods of contact were also mentioned; some parents preferred telephone calls while others preferred email communication.

Many parents expressed that more frequent contact at the beginning of the intervention (closer to the diagnosis) was an important support and reinforcement of previous teaching. All parents described being overwhelmed at the time of diagnosis. In this context, the parents stated that the parent mentor initiating contact was helpful as they may not have been able to make the initial telephone call to the parent mentor. Parents stated that as time passed, they often had less frequent contact with the parent mentors, but the underlying sense of support and the opportunity to call the parent mentors at any time remained a valuable source of reassurance. A few parents referred to their STEP parent mentors as friends who remained in touch after the formal intervention (12 months duration) was completed. One mother stated, “The parent mentor was there for me all the time. She gave me her cellphone number and everything; she even said I could call her if I needed her when she was on vacation!”

Practical tips

The second major theme was *practical tips*. The day-to-day management of T1DM is time-consuming and needs to be quickly learned following diagnosis. When asked to list topics discussed with the parent mentors, all parents consistently described conversations covering numerous practical tips. The “nitty gritty” of day-to-day management of T1DM was a subject emphasized by all interviewees. Parent mentors provided practical information during face-to-face conversations, telephone calls, and email contacts. Parents described the parent mentors sharing “what works, what doesn’t, and when to call (the doctor).”

Practical tips parents mentioned included packing for outings, ordering the proper amount of supplies, buying food scales, working with school nurses, educating babysitters, and identifying support groups. Other tips parents discussed with parent mentors were how different foods react with different children, suggestions for appropriate drink choices, and types of glucometers. Parents identified strategies parent mentors discussed for working effectively with members of the healthcare team as an essential piece of information. One father stated that *the* important part of the parent mentor’s contact was “being able to ask questions, getting help when asking questions, getting an honest answer.”

Common ground

Common ground was the third theme that was consistent with all parents. One father simply stated that the parent mentor was “someone who got it.” During interviews parents consistently declared that only parents who are raising children diagnosed with diabetes can know what they are experiencing. All parents discussed that the parent mentors shared similar emotions following the child’s diagnosis and they did endure. These conversations were confirmations of shared experience. Parents stated that during face-to-face, telephone, and/or

email contacts the parent mentors often validated their feelings and helped build confidence in their day-to-day management of diabetes. Parents described that parent mentors repeatedly shared the understanding that there have been, and will be, difficult days.

The adaptation of the family to the child's diagnosis was also described by three mothers. Parents with more than one child stated that they were appreciative that parent mentors shared the need to maintain family balance. As one mother stated "... if the sick child is always the focus, that can really make things very yucky for the other kids." Several parents responded that the parent mentors had discussed the return to a normal life.

Parents described parent mentors sharing that this life will be different from the life prior to the diagnosis of T1DM. This life will be a new normal. Parents expressed that it was helpful hearing stories of the parent mentors' experiences with the shock of diagnosis and interactions with healthcare professionals, family members and friends. Parents described that seeing the children of the parent mentors leading normal lives helped them better understand that life does go on. Parents responded that parent mentors discussed their children going out to dinner, traveling, participating in sports, and being involved in school activities. One mother stated that the parent mentor stressed that parents can live a normal life, too. This mother described the parent mentor's expressing that if I can do it, you can do it, too. The theme of *common ground* was summarized as one mother succinctly stated: "The parent mentor made you feel like you're not the only one going through this."

Additional information

Three parents, one mother and one mother/father dyad, stated that the contact with the parent mentor was limited and they did have support from other sources. The majority of parents expressed the high level of comfort during interactions with the parent mentors and the ease of

discussion. The parents interviewed by this researcher were aware that there were other parents who were not in the intervention arm of the STEP RCT. Unanimously, parents articulated that all parents of children newly diagnosed with T1DM should have the opportunity to be contacted by and have a parent mentor.

Suggestions for improvement of the STEP intervention included contacting parents and providing face-to-face contact (if at all possible) while the child is still in the hospital. Several parents described that this strategy would provide parents with a veteran parent to contact “right away for the questions and concerns.” One mother expressed some confusion with the STEP on-line surveys. She questioned why the same surveys were being used repeatedly, responded that the surveys were confusing, and that the surveys could be “streamlined.” When asked for a suggestion for streamlining the surveys, the mother responded that she thought many of the questions were not pertinent to the diagnosis of T1DM and/or the contact with the parent mentors. Another mother suggested asking parents if they would prefer contact primarily via telephone calls or via emails during the 12- month intervention. An additional suggestion for improvement from one mother was, if at all possible, to assign a parent mentor with a child a bit older than the newly-diagnosed child in order to “see what’s ahead.”

Aim 2: Describe parents’ day-to-day diabetes management as measured by the Family Management Measure (FaMM) (six scales: child’s daily life, condition management ability, condition management effort, family life difficulty, parental mutuality and view of condition impact).

FaMM Results

Eleven of the parents completed the FaMM (8 mothers and 3 fathers). Two mothers who were unable to participate in interviews completed and returned the FaMM to this investigator via mail. These data were not included in the data analysis as the parents were not interviewed. The demographic data were run on these 11 parents, with missing data for one parent (parent's age, education, marital status, employment status, and ethnicity). Level of education data were missing for an additional 4 parents. Parents ranged in age from 22 to 43 years old, with a mean of 36 years (median = 37 years). The majority of parents identified themselves as White ($n = 8$; 80%) and had a post-secondary education ($n = 5$; 83%). Fifty percent of the parents ($n = 5$) worked full or part-time.

Aim 2 is presented with quantitative data. The FaMM (Table 6) was used to depict parents' day-to-day management of the chronic illness T1DM. Descriptive statistics (mean, median, range and frequency) (Table 7) for the six scales of the FaMM were run for each scale: Child's Daily Life (CDL), Condition Management Ability (CMA), Condition Management Effort (CME), Family Life Difficulty (FLD), View of Condition Impact (VCI), and Parental Mutuality (PM). Normal distribution was noted for all FaMM scales.

Table 6

FaMM Scales, Description and Score

Scale	Description	Score/Score Range
Child's Daily Life (CDL)	Perceptions of child and his/her everyday life	Higher scores reflect more normal life / 5-25
Condition Management Ability (CMA)	Perceptions of parents' competence to care for child's condition	Higher scores reflect more competence in care/ 12-60
Condition Management Effort (CME)	Perceptions of parental work needed to manage the child's condition	Higher scores reflect more parental effort / 4-20
Family Life Difficulty (FLD)	Perceptions of the extent to which management of the child's condition makes life more difficult	Higher scores reflect more difficult family life / 14-70
View of Condition Impact (VCI)	Perceptions of seriousness of the child's condition and its implications for the child and family	Higher scores reflect great impact / 10-50
Parental Mutuality (PM)	Satisfaction with how partners work together to manage child's condition	Higher scores reflect more satisfaction /8-40

Table 7

Family Management Measurement (FaMM) Scales: Descriptive Statistics

FaMM Scale	Mean	Median	Potential Range	Actual Range
Child's Daily Life	18.73	19	5-25	11-24
Condition Management Ability	50.55	52	12-60	38-60
Condition Management Effort	13.82	13	4-20	11-19
Family Life Difficulty	28.27	25	14-70	15-51
View of Condition Impact	25.55	23	10-50	18-38
Parental Mutuality	31.27	31	8-40	9-40

N = 11

All parents (N=11) completed the six FaMM scales. The mean score on the Child's Daily Life Scale in this sample was 18.73. Scores ranged from 11 to 24 (potential range 5-25), with higher scores reflecting the parental perception of a more normal life. The scores of 16 and 22

had the frequency of 2 each, each of the other scores (11, 15, 17, 19, 21, 22, 23, 24) having the frequency of 1 each.

The Condition Management Ability scale mean was 50.55, with a range of scores 38 to 60 (potential range 12-60). Higher scores on this scale reflect parental perception of more competence to care for the child's condition. The score with the highest frequency (3) was 52, while scores 48 and 55 had frequency of 2. All other scores (38, 40, 56, 60) had the frequency of 1.

The Condition Management Effort scale mean was 13.82, with scores ranging from 11 to 19 (potential range 4-20), with higher scores reflection parental perceptions for more effort required to manage the child's condition. The highest frequency (3) was the score of 11. The scores 12, 13, and 16, had the frequency of 2, while scores 18 and 19 had the frequency of 1.

The Family Life Difficulty scale mean was 28.27, with scores ranging from 15 to 51 (potential range 14-70). Higher scores on this scale reflect parental perceptions of a more difficult family life due to the management of the child's condition. The score of 25 had a frequency of 2, while all other scores (15, 20, 21, 22, 24, 32, 36, 40, 51) had a frequency of 1.

The View of Condition Impact scale's mean was 25.55 in this sample of 11 parents, with scores ranging from 18 to 38 (potential range 10-50). Higher scores on this scale reflect parental perceptions of the seriousness of the child's condition and a greater impact on the family. The score with the highest frequency (3) was 32, the score of 19 a frequency of 2, while the other scores (18, 20, 21, 23, 27, 38) each a frequency of 1.

The mean for the sixth scale, Parental Mutuality, was 31.27 in this sample (8 mothers and 3 fathers). The scores ranged from 9 to 40 (potential range 8-40), with higher scores reflection parental satisfaction with how partners work together to manage the child's condition.

The score of 31 had the highest frequency (5) while all other scores (9, 28, 36, 37, 39, 40) had the frequency of 1.

Despite the small sample ($n = 11$), internal consistency reliability was assessed for the six scales of the FaMM. Scores for mothers and fathers were combined with this small sample and displayed in Table 8. Internal consistency reliability was good with Cronbach's alpha at least .80 for five of the six FaMM scales: Child's Daily Life (.80), Condition Management Ability (.86), Family Life Difficulty (.90), View of Condition Impact (.83), and Parent Mutuality (.91). Only one scale, Condition Management Effort, had a low alpha at .50.

The Child's Daily Life, Condition Management Ability, View of Condition Impact and Parental Mutuality scales internal consistency reliability scores in this small, purposeful sample were higher than those reported for both mothers and fathers by Knafl et al. in a significantly larger sample (2009). The Family Life Difficulty scale's Cronbach's alpha in this sample was .90, similar to Knafl et al.'s larger sample (mothers = .90; fathers = .91). The internal consistency reliability of the remaining scale, Condition Management Effort (4 items), was not acceptable at .50, compared to Knafl et al.'s report of .74 for mothers and .78 for fathers (2009).

Table 8

Family Management Measurement (FaMM) Scales and Internal Consistency Reliability

FaMM Scale	Internal Consistency Reliability
Child's Daily Life (CDL) (5 items)	.80
Condition Management Ability (CMA) (12 items)	.86
Condition Management Effort (CME) (4 items)	.50
Family Life Difficulty (FLD) (14 items)	.90
View of Condition Impact (VCI) (10 Items)	.83
Parental Mutuality (PM) (8 items)	.91

N = 11

Dyad information

Because of the small number of parent dyads ($n = 3$), results from the six FaMM scales were clustered by individual parent dyad (Table 9) for comparison. Among the three parent dyads, scale score difference ranged from no difference (equal scores on a scale) on to a 31-point difference on the Parent Mutuality scale. The first parent dyad (1D and 1M) had scale score difference ranging from no point difference to 25 points. The second parent dyad (2D and 2M) had scale score difference ranging from no point difference to 9 points apart. The final parent dyad (3D and 3M) had FaMM scale score differences from 7 to 31 points apart. This parent dyad had results ranging from a 7-point difference on the Condition Management Effort scale to a 31-point difference on the Family Life Difficulty scale. This dyad also had a 28-point difference on the Parent Mutuality scale, with the mother reporting a score of 9 (indicating lower satisfaction with how partners work together to manage the child's condition) and the father reporting a score of 37 (the potential maximum score is 40). This was the largest difference on the Parent Mutuality score of all three dyads, with another dyad reporting the same score (31) and the third dyad reporting an 8-point difference (mother = 31; father = 39).

Table 9

Parent Dyads: FaMM Scale Scores

Parent Dyad	CDL Higher scores = more positive life	CMA Higher scores = greater competence to care for child	CME Higher scores = greater parental effort required	FLD Higher scores = more difficult family life	VCI Higher scores = greater impact	PM Higher scores= more satisfaction with partners working together
1D	15	52	19	40	38	31
1M	24	60	11	15	18	31
(+/-)	+9	+8	-8	-25	-20	0
2D	22	55	16	22	32	39
2M	22	48	13	25	23	31
(+/-)	0	-7	-3	+3	-9	-8
3D	19	56	11	20	20	37
3M	11	40	18	51	32	9
(+/-)	-8	-16	+7	+31	+12	-28

(M= Mother D= Father)

The Child's Daily Life scale scores ranged from 11 to 25, with one dyad (2D and 2M) reporting identical scores. The remaining parent dyads had 8 (3D and 3M) - and 9-point (1D and 1M) differences. The Condition Management Ability scale scores ranged from 40 to 60, with the first parent dyad reporting an 8-point difference, the second dyad a 7-point difference and the third dyad a 16-point difference. On the Condition Management Effort scale, parents' scores ranged from 11 to 19. Dyad differences were 3 points (2D and 2M), 7 points (3D and 3M) and 8 points (1D and 1M). The Family Life Difficulty scale scores ranged from 15 to 51 in these dyads. Score differences were 3 points (2D and 2M), 25 points (1D and 1M) and 31 points (3D and 3M). The fourth scale, View of Condition Impact, had parental scores ranging from 18 to 38. Differences in dyad scores were 9 points (2D and 2M), 12 points (3D and 3M) and 20 points (1D and 1M). The Parent Mutuality scale had scores ranging from 9 to 39. One parent dyad (1D and 1M) had no difference in score, while the other dyads had an 8-point difference (2D and 2M) and a 28-point difference (3D and 3M).

Aim 3: Describe the relationship between parental management scores in the 6 FaMM scales and the social support intervention dose used.

Aim 4: Explore FaMM scores in relationship to parent satisfaction with the STEP social support intervention.

Descriptive Matrices

With this small sample, statistics are limited to description only and are depicted in matrices with the FaMM scale scores in Table 10 and Table 11. Intervention dose was measured as the total number of minutes spent in interactions between parent mentors and parents. Parent mentors provided support via home visits, telephone calls, and/or e-mail communication. The number of intervention dose minutes (any interaction greater than 5 minutes) and the number of parent mentor contacts were documented by the parent mentors during the STEP intervention. Statistics were run for intervention dose (in minutes) and the number of parent mentor contacts.

Mothers in the STEP RCT were always available during the contact episodes. It is not clear when the fathers were present, or for what portion of time, during the parent mentor contact, since these data were not collected during the STEP RCT. Thus, only the mothers' data will be described ($n = 8$). The intervention doses (in minutes) ranged from 0 minutes to 2805 minutes (mean = 452.73 minutes, median = 277 minutes) over the 12-month trial. Parent mentor contacts ranged from 3 contacts to 25 contacts with a mean of 8.13 contacts and median of 5.5 contacts. Eight mothers completed the FaMM. One mother had 3 parent mentor contacts, two mothers had 4 parent mentor contacts, one mother had 5 parent mentor contacts, one mother had 6 parent mentor contacts, two mothers had 9 parent mentor contacts and one mother had 25 parent mentor contacts.

One mother had 25 mentor contacts and an intervention dose of 2805 minutes. With this outlier removed ($n = 7$), descriptive statistics were run again. Intervention dose (in minutes) ranged from 0 to 510 minutes (mean = 217.5 minutes, median = 265 minutes) and parent mentor contacts ranged from 3 to 9 contacts (mean = 5.71, median = 5). The results of the FaMM's 6 scales were compared with the intervention dose (number of minutes) and number of contacts each mother had with the parent mentor. Again, only the mothers' (all married) data were used to develop the matrices.

Table 10

Intervention Dose in Minutes and Mean FaMM Scales Scores

Intervention minutes	<i>n</i>	CDL	CMA	CME	FLD	VCI	PM
100-200	1	11	40	18	51	32	9
201-300*	3	19	56	12	24	24	33
301-400**	2	20	45	14	30	23	30
401-500	-	-	-	-	-	-	-
501-600	1	22	48	13	25	23	31
601+	1	21	48	12	21	19	40

(Mothers only: $n = 8$)

*200-300: mean = 271.7 minutes

**300-400: mean = 342.5 minutes

The one mother with the lowest intervention dose minutes (167) had scores on four of the six FaMM scales that were notably above or below the mean. On the Child's Daily Life scale (potential range 5-25), the score was 11 (mean = 18.73), indicating the perception of the child and his/her daily life as less normal. On the Family Life Difficulty scale, this mother had a score of 51, well above the mean of 28.27. Higher scores on this scale (potential range 14-70) indicate a more difficult family life. This mother scored 9 (mean = 31.27) on the Parent Mutuality scale (potential range 8-40), in which higher scores reflect more satisfaction with how parents work together on managing the child's condition.

On the Child's Daily Life scale, higher mean scores were reported for those mothers receiving greater than 201 minutes of parent mentor contact, indicating perceptions of a more normal everyday life. Lower mean scores were reported for those mothers receiving 201-300 and 501- 601+ intervention minutes on the Condition Management Effort scale (indicating the perception of less effort to manage the child's condition). There were no mothers who received between 401 and 500 intervention minutes as indicated in Table 10.

The number of parent mentor contacts and the mean FaMM scale scores are displayed in Table 11. Parent mentor contacts ranged from 1-25 over the 12-month intervention. As indicated in the table no mothers received between 11 and 20 parent mentor contacts. On the Child's Daily Life (CDL) scale, there is a 4 point increase (17 to 21) for those mothers who received 6 or more parent mentor contacts, but no difference in the mean scores between mothers who received 6 to 10 parent mentor contacts and 20 to 25 parent mentor contacts. Mothers' mean scores on the Condition Management Ability (CMA) scale were similar and ranged from 48-50. The lowest score (48) was reported from the mother with the highest number of parent mentor contacts.

Mean scores (per intervention dose) on the Condition Management Effort (CME) was 13 (possible score 4-20). The one mother who received 20-25 parent mentor contacts had a score of 12. Mothers' mean scores on the Family Life Difficulty (FLD) scale (possible score 14-70) ranged from 21-33 (lower scores indicate a perception of a less difficult family life). The one mother who received the most parent mentor contacts reported the lowest score. The View of Condition Impact (VCI) scale (possible scores 10-50) mean scores ranged 5 points from 19 to 26, with higher scores indicating a greater impact of the seriousness of the child's condition and its implications for the child and family. Mothers receiving 1 to 5 parent mentor contacts had a mean score of 26, while mothers receiving 6 to 10 parent mentor contacts had a decrease of 3

points to a score of 23. As with the Family Life Difficulty scale, the mother who received 25 parent mentor contacts reported the lowest score (19). The sixth scale, Parental Mutuality (PM) has possible scores ranging from 8 to 40 (higher scores reflecting more satisfaction with how the partners work together to manage the child's condition). Mothers' mean score of 25 for those receiving 1 to 5 parent mentor contacts increased 5 points to 30 for those receiving 6 to 10 parent mentor contacts. The Parent Mutuality scale score for the mother who received the most parent mentor visits was 40.

Table 11
Parent Mentor Contacts and Mean FaMM Scale Scores

Parent Mentor Contacts	<i>n</i>	CDL	CMA	CME	FLD	VCI	PM
1-5	4	17	50	13	33	26	25
6-10	3	21	49	13	25	23	30
11-15	0	-	-	-	-	-	-
16-20	0	-	-	-	-	-	-
20-25	1	21	48	12	21	19	40

(Mothers only: *n* = 8)

During the interviews conducted by this investigator all parents (*n* = 13) were asked to rate their satisfaction with the STEP RCT intervention on a scale of 1 (*not satisfied*) to 5 (*highly satisfied*). All parents enthusiastically answered "A 5." This rating was unanimous with mothers only and mother-father dyads, regardless of scores on all FaMM scales.

Summary

This study highlighted the experiences of parents involved in the intervention arm of the STEP RCT. In summary, three major themes of support emerged from the parents' responses during interviews following the 12-month intervention: *availability*, *practical tips*, and *common ground*. All parents interviewed consistently described parent mentors as available for questions and concerns, sharing practical tips for managing the illness, and having "been there" as a parent

of a child with T1DM. Parents overwhelmingly expressed the desire that all parents could receive the support of a parent mentor. Suggestions for improvement of the STEP RCT intervention included providing face-to-face contact with a parent mentor while the newly-diagnosed child is still in the hospital, simplifying the on-line surveys, asking parents if they would prefer telephone call or e-mail contacts during the intervention, and assigning a parent mentor with a child “a bit older” than the newly-diagnosed child.

Quantitative data from this small purposeful sample, gathered using the FaMM, was limited to description only. Due to the small number of parents and variation among parent dyads, matrices were developed depicting FaMM scale scores and intervention dose as well as FaMM scale scores and the number of parent mentor contacts.

Despite the small sample ($n = 11$), internal consistency reliability was assessed for the six scales of the FaMM. Scores for mothers and fathers were combined with this sample. Internal consistency reliability was acceptable (Cronbach’s alpha at least .70) for five of the six scales: Child’s Daily Life, Condition Management Ability, Family Life Difficulty, View of Condition Impact, and Parental Mutuality. One scale, Condition Management Effort, was .50. Therefore, five of the FaMM’s scales had good reliability in this purposeful sample. These qualitative and quantitative results may inform research, policy and practice, which will be discussed in Chapter V.

Chapter V Discussion

The purpose of this mixed-methods descriptive study was to explore parents' experiences with peer social support following the STEP RCT intervention and to examine the usefulness of the Family Management Measure (FaMM) in this population. This topic is of importance because of the increased incidence of Type 1 diabetes (T1DM) in children under the age of 12. The initial diagnosis requires that parents adapt to significant changes in family life, including the demands of managing this life-changing illness. Parental day-to-day management of children with T1DM requires a working knowledge of the disease process and potential complications. Families can learn to cope with the day-to-day tasks of managing the disease if they receive medical and emotional support.

The themes that emerged (availability, practical tips and common ground) were similar to Ireys' three essential social support components: informational, affirmational, and emotional (Ireys et al., 1996). Thus, Ireys et al.'s social support framework helped explain parents' experiences in this study. The theme of *availability* is similar to the emotional social support component, *practical tips* is similar to the informational support component; and *common ground* is similar to the affirmational support component.

These findings are also consistent with Ireys et al.'s RCT findings, where he tested a 15-month social support intervention for mothers (N= 48) of children with Juvenile Rheumatoid Arthritis that provided emotional, informational, and affirmational support using peer mentors (Ireys et al, 1996). Ireys et al. (2001) defined social support as information leading people to believe they are esteemed and valued and that they belong to a network of mutual obligations. According to Ireys, social support for parents of children with a chronic illness can potentially

decrease parental distress (Ireys, Chernoff, DeVet & Kim, 2001; Ireys, Chernoff, Stein, DeVet & Silver, 2001; Ireys, Sills, Kolodner & Walsh, 1996).

These qualitative findings were consistent with other findings related to parents' experiences with peer social support following the diagnosis of their children with chronic illnesses (Chernoff et al., 2002; Ireys et al., 2001; Ireys et al., 1996; Nicholas & Keilty, 2007; Sullivan-Bolyai et al., 2004; Sullivan-Bolyai et al., 2010; Symon, 2005). Across the studies, parents reported parent-to-parent social support helped them feel less isolated, provided strategies to help with adjustment, and reported reduced mental health symptoms, including decreased stress (Chernoff et al., 2002; Ireys et al., 2001; Ireys et al., 1996; Nicholas & Keilty, 2007; Sullivan-Bolyai et al., 2004; Sullivan-Bolyai et al., 2010; Symon, 2005).

Parents discussed the need to quickly learn illness management. As reported by Sullivan-Bolyai, Knafl, Sadler, and Gilliss (2003), managing T1DM includes knowing about the illness and treatment plan, including daily hands-on care and interpretation of signs and symptoms of complications. Parents also shared that they must educate others (family members, babysitters, school nurses) to care for their child. Children diagnosed with T1DM require specialized care by those knowledgeable or willing to be educated in the day-to-day management of this chronic illness. These findings are consistent with illness management needs described by Sullivan-Bolyai et al. (2003).

Parents' description of the common ground they had with the parent mentor, or the understanding of a parent who had "been there" is similar to findings of Ainbinder et al. (1998) who conducted a qualitative descriptive study to explore mothers' and fathers' ($n = 24$) experiences with a parent-to-parent program for families with children with special needs. As Ainbinder et al. (1998) reported, a successful parent-mentor relationship depended on perceived

“sameness,” a situational comparison that enabled learning and growth, around-the-clock availability of support, and mutuality of support. Perceived sameness was found to be the most basic principle of self-help support. This perception was established because the support giver (parent mentor) typically had experienced the same challenges as the support recipient (parent of newly diagnosed child) (Ainbinder et al., 1998).

Parents in this study emphasized communication with someone who had similar experiences and affirmation of their management of the chronic illness. Nicholas and Keilty’s (2007) qualitative findings with parents of children dependent upon technology due to chronic lung disease suggested that a social support intervention provided communication with someone who understood what the caregivers were experiencing, thus it decreased their social isolation and enhanced learning (Nicholas & Keilty, 2007).

Previous research with parents of children newly diagnosed with T1DM is found in the literature. Qualitative data from Sullivan Bolyai et al.’s feasibility study Helping Other Mothers Effectively Work at Raising Young Children with Type 1 Diabetes (HOMEWARD) suggested that the parents who received peer social support had less concern, increased feelings of confidence, and had gained much-needed practical information on managing their child’s T1DM on a daily basis (Sullivan-Bolyai et al., 2004). However, the quantitative portion of the STEP intervention RCT (Sullivan- Bolyai et al., 2010) did not show significant findings for the mothers. The findings included no differences between the two groups at 3, 6, and 12 months in parental concern, confidence, worry, impact on the family, or perceived social support. The positive qualitative findings suggest further exploration is needed as to what actually helped parents that wasn’t measured in the study.

As in the HOMEWARD study, parents in this qualitative portion of the study described that the parent mentors helped them see the “big picture,” learn practical ways to fit diabetes into family life, and not let the child’s illness dictate life. The identified themes of availability, practical tips, and common ground described by parents in this study further supported the HOMEWARD findings. These qualitative findings can serve as an interview guide to revisit participants in the STEP intervention in focus group settings. As a follow up to the STEP RCT, focus groups are planned (Sullivan-Bolyai et al., 2010). The investigators will conduct focus groups using these qualitative findings to further clarify the mechanisms by which the intervention works and how parents of children newly diagnosed with T1DM best receive social support. These data may also contribute in the development of a social support instrument that may better capture the value of parent mentor peer social support (Sullivan-Bolyai et al., 2010).

In addition, the results from this study support the recommendations made by parents in a recently reported pilot study of a telephone-based supportive intervention for parents of young children (age 2-5 years) who had been diagnosed with T1DM a minimum of 6 months (Monaghan, Hilliard, Cogen, & Streisand, 2010). Recommendations from the parents ($n=15$) in this study indicated the desire for increased social support, resource information, the opportunity to have contact with other parents, and the indication that the program could be particularly helpful closer to the time of child’s diagnosis (Monaghan et al., 2010).

Analysis of the use of the FaMM in this population was limited to description only, due to the small sample size, but important family management issues beg for future exploration and testing. The FaMM only recently has been made available for testing. There are currently no published studies using the FaMM in a population limited to parents of children with T1DM.

Previous studies consisted of large numbers of parents of children diagnosed with a variety of chronic illnesses (Knafl et al., 2010).

Recently, Knafl et al. (2010) reported a cluster analysis of results on the FaMM scales. Knafl et al.'s sample was 575 parents of children aged 2- 18 years with a chronic condition. The mean scale score range was reported for mothers and fathers. Mean scores for each FaMM scale from this sample fell within the mean score ranges reported. The mean score on the Child's Daily Life Scale in this sample was 18.73, falling in the range of Knafl et al.'s reported mean scale scores of 11-22 for mothers and 12-23 for fathers. In this sample, the Condition Management Ability scale mean was 50.55; Knafl et al.'s mean score ranged from 38- 53 for mothers and 43-54 for fathers. The Condition Management Effort scale mean was 13.82, while Knafl et al.'s reported mean ranged from 8-17 for mothers and 9-16 for fathers. The Family Life Difficulty scale mean in this sample was 28.27, with the mean range reported 20-53 for mothers and 19-49 for fathers. The View of Condition Impact scale's mean was 25.55 in sample of 11 parents, with Knafl et al.'s mean ranging from 22-34 for mothers and 20-34 for fathers. The mean for the fifth scale, Parental Mutuality, was 31.27 in this sample; the ranges in Knafl et al.'s larger sample ranged from 29-36 for mothers and 32-37 for fathers. In this small sample, each FaMM mean score was within the results reported from the larger study.

The ranges in FaMM scale scores in this sample were compared to the mean score ranges reported in Knafl et al.'s larger sample. Mothers and fathers were combined in this small sample. Two FaMM scales had similar ranges to Knafl et al.'s mean score ranges: Child's Daily Life and the Condition Management Effort. The Child's Daily Life scale range was 13 points in the STEP sample while Knafl et al.'s were 11 points in mothers and 12 points for fathers. The Condition Management Effort scale in the STEP sample had a score range of 8 points, with

Knafl et al.'s larger sample mean ranging 9 points for mothers and 7 points for fathers. The remaining four FaMM scales had wider ranges in the STEP sample than the participants in Knafl et al.'s study. The View of Condition Impact scale had a 20-point range compared to the 12 points in mothers and 14 points for fathers. The Condition Management Ability scale range was 22 points in the STEP sample compared to the 15-point range for mothers and 11-point range for fathers. The Family Life Difficulty scale scores in the STEP sample had a 36-point range while the same scale in the larger study had ranges of 33 points in mothers and 30 points in fathers. The largest difference in ranges noted was the Parental Mutuality scale with a larger range of 31 points in the STEP sample compared to Knafl et al.'s 9 points in mothers and 5 points in fathers.

The internal consistency reliability of 5 of the 6 FaMM scales in this sample was similar to results reported by Knafl et al. (2009). In this small sample, mothers and fathers were combined. Knafl et al.'s reports on internal consistency reliability of the six scales described mothers' and fathers' scores independently (2009). The Child's Daily Life, Condition Management Ability, View of Condition Impact and Parental Mutuality scales internal consistency reliability scores in this small, purposeful sample were higher than those reported for both mothers and fathers by Knafl et al. in a significantly larger sample (2009). The Family Life Difficulty scale's Cronbach's alpha in this sample was .90, similar to Knafl et al.'s larger sample (mothers = .90; fathers = .91). The internal consistency reliability of the remaining scale, Condition Management Effort (4 items), was considered not acceptable at .50, compared to Knafl et al.'s report of .74 for mothers and .78 for fathers (2009). This result may be related to the small number of items and the small sample size, as Cronbach's alpha is dependent on the number of items on a scale.

In the three parent dyads in this study, FaMM scale scores were not similar to the mean scores recently reported by Knafl et al. (2010). The parent dyads' mean scale differences on the scales ranged 0-25 points (dyad 1), 0- 9 points (dyad two) and 7-31 points (dyad 3). Knafl et al. (2010) reported that mean scale scores in parent dyads differed by 1-2 points in those clustered and referred to as effective management. Parent dyads in the problematic management cluster had mean scale scores differ between 0-5 points. The differences among partners are speculative, but do provide interesting information about parental day-to-day management and co-parenting.

The differences in FaMM scale scores may be similar to the differences in perception of co-parenting and family function reported by Gavin & Wysocki (2006). In research with parents of children with chronic illnesses, the results supported a relationship between fathers' reports of their own involvement with the child's care with marital satisfaction and family adjustment, but not with mother's self-reported psychological adjustment (Gavin & Wysocki, 2006). Mothers of children with T1DM have higher levels of emotional symptoms compared with fathers (Haugstvedt, Wentzel-Larsen, Rokne, & Graue, 2010). The greater perceived burden of medical treatment in children with T1DM may be explained as mothers are often the primary caregivers and the coordinator of the child's care. Mothers who are unsupported by fathers may need added resources to help them in the day-to-day management of diabetes care (Worrall-Davies, Owens, Holland & Haigh, 2002). Wysocki & Gavin (2006) reported that mothers' and fathers' responses indicated that more paternal involvement was related to more favorable outcomes in marital satisfaction and family functioning. Maternal report of higher ratings on the measurement tool was associated with fewer self-reported maternal psychiatric symptoms and less perceived impact of the chronic illness on family functioning. Higher collaborative involvement, particularly among primary caregivers, was associated with favorable status along a variety of

diabetes outcomes (Wysocki & Gavin, 2006). A study with parents of children with T1DM reported collaborative parent involvement in diabetes care was associated with higher levels of health-related quality of life (Weissberg-Benchell et al., 2009).

It would be interesting to further investigate the level of involvement in day-to-day care of the father whose scores on the Family Life Difficulty and View of Condition Impact scales drastically contrasted with his wife's scores. As described by Sullivan-Bolyai, Rosenberg, and Bayard (2006), most fathers involved with their child's diabetes care reported the importance of learning required skills, staying involved with disease management, and "co-parenting" to share responsibilities. With the small number of fathers ($n = 3$), limited data were provided. These data may be fodder for future work with the FaMM.

The number of parent mentor contacts may also be influential in the difference in mean scores on some of the FaMM scales. This may indicate need to investigate the effectiveness of a higher intervention dose. This may be an area that warrants further investigation to structure optimal peer social support interventions. In addition, Sullivan-Bolyai et al. (2010) have reported plans to clarify the mechanisms needed to determine how the STEP intervention works and how parents of newly diagnosed children with chronic illnesses best receive social support. The use of the FaMM scales may be an instrumental tool in this clarification.

In summary, the qualitative data analysis illustrated that the intervention in the STEP RCT was effective in supporting the emotional, affirmational, and informational social support in Ireys' framework and the satisfaction of the parents interviewed. The data will be utilized to structure an interview guide to be used in future focus groups. The use of the FaMM in this population was a first step in implementing this instrument but it will be interesting to further

explore its use in a variety of populations and at an array of times in the course of a child's chronic illness.

Implications for Practice

The findings in this study, despite non-significant findings in the quantitative portion of the larger STEP study, identified a structured peer social support intervention as a beneficial strategy for parents of children less than 12 years of age newly diagnosed with T1DM. Nurses are at the frontline, educating and supporting parents through this critical time. Nurses should assess their clients for the level of perceived social support, availability of support, actual support received, costs of support, and changes in support over time. Nurses, instrumental in providing resources for patients and families, may make known the benefits of and opportunities for peer social support to the parents of children newly diagnosed with T1DM. In these situations, nurses can intervene to promote or strengthen social support resources for their clients (Schaffer, 2009).

Further use of the FaMM scales in a variety of populations is essential. Use of the FaMM initially at the child's diagnosis of T1DM, then at specific intervals throughout the first year, may provide insight into support and education needs as families transition into managing this chronic illness. Use of the FaMM at initial diagnosis of a child's T1DM may help identify the initial family management style, develop family interventions, and develop strategies to best work with parents to move towards more effective management of the child's chronic illness. As Knafl et al. (2009) have recommended, the FaMM would be useful to assess parents' perceptions of family strengths and areas of difficulty, identifying where intervention may be necessary. Use of the FaMM scales in partnered parents of children newly diagnosed with chronic illnesses may increase parental mutuality and coordination of care. One strategy may be to have parents independently complete the FaMM scales and compare the parental dyad's scores on each scale.

Following the comparison, parental dyads with widely disparate scores may benefit from family intervention to work towards a partnership in caring for their child and their family.

As noted in the STEP RCT, there may have been a selection bias in referrals to the RCT. After the study had closed, members of the diabetes teams at the recruitment sites indicated that some parents were perceived to be too overwhelmed and were not referred for the RCT. Unanimously, parents interviewed for this study indicated that all parents should be offered parent mentors, even if they appear overwhelmed. Parent mentors initiating contact or visiting in person shortly after diagnosis was also suggested.

Implications for Research

STEP RCT

This study added knowledge regarding parents' experiences with a parent mentor social support intervention when their child (< 12 years of age) was newly diagnosed with T1DM. Statistical analyses from the quantitative portion of the STEP RCT demonstrated no significant difference (Sullivan-Bolyai et al., 2010) in outcome measures of parents in the intervention and control arms of that study. However, the qualitative data reported here strongly supports the positive impact of the intervention for this population. Two parents did mention confusion with the completion of the on-line survey instruments in the STEP RCT. These on-line surveys will also be a topic for discussion with planned focus groups to further investigate confusion or problems with the completion of these instruments.

There is a need to further investigate the relationship between the Sullivan-Bolyai et al.'s (2010) non-significant findings and these qualitative findings. These qualitative findings can serve as an interview guide to revisit participants in the STEP intervention in focus group settings. As a follow up to the STEP RCT, focus groups are planned (Sullivan-Bolyai et al.,

2010). The investigators in the STEP RCT plan to use the focus group data to further clarify the mechanisms by which the intervention works and how parents of children newly diagnosed with T1DM best receive social support. These data may work towards developing instruments that may better capture the value of parent mentor peer social support (Sullivan-Bolyai et al., 2010).

FaMM

The FaMM is currently in limited use. The use of this instrument in a larger study of parents of children newly diagnosed with T1DM would contribute to the knowledge base. Expanded use of the FaMM among a larger sample of participants is necessary. Knafl et al. (2010) used FaMM scales cluster analysis to identify family management styles: Effective Management, Problematic Management, Somewhat Effective Management, and Somewhat Problematic Management. Use of the FaMM in family intervention research could also target the FaMM dimensions of Child's Daily Life, Condition Management Ability, Condition Management Effort, Family Life Difficulty, Parent Mutuality, and View of Condition Impact. The inclusion of the FaMM may provide a more precise lens into day-to-day management of chronic illness. These quantitative data may refine parent-mentor interventions, thus informing future social support research.

Implications for Health Care Policy

With the increase in frequency of T1DM diagnosis in young children, providing support to parents is essential. Nurses advocating for the inclusion of formal peer social support intervention in T1DM management and its cost covered by health insurance may improve both physical and psychological outcomes for children with T1DM. Use of parent peer social support programs with carefully selected and trained mentors may increase satisfaction with the program,

may provide education for appropriate clinic and hospital follow-up, and may reduce overall health insurance costs for family and the insurer.

The diagnosis and treatment of a child's T1DM constitute traumatic events for parents (Landolt, Vollrath, Laimbacher, Gnehm, & Sennhauser, 2005). These traumatic events can result in posttraumatic stress disorder (PTSD). PTSD in parents of children newly diagnosed with T1DM has been documented in the literature (Antje, Freda, Paul, & Julie, 2007; Horsch et al., 2007; Landolt et al., 2002; Landolt, Vollrath, et al., 2005). In light of the literature that has identified extreme stress with increased healthcare costs, family functioning, and overall individual well-being, the impact of the diagnosis of PTSD in parents on the family and child's daily care can be overwhelming (Walker et al., 2003). Offering a parent support program may be one resource to help decrease the emotional trauma that many of these parents may experience.

Recommendations for clinical practice included the importance of integrating medical and psychosocial support for parents of children newly diagnosed with T1DM (Horsch et al., 2007; Stoppelbein & Greening, 2007). Use of the FaMM following the child's diagnosis of T1DM may enhance assessment of parental support needs. The inclusion of support interventions, both professional and peer, may decrease the incidence or severity of PTSD. With early and effective interventions, costs incurred treating PTSD in parents of children newly diagnosed with T1DM may be reduced.

Limitations

There are several limitations in this study. The parents in this study are a purposive sample of those parents enrolled in the STEP RCT intervention, using a one-time interview. This small sample limits generalizability to the larger population of parents with children diagnosed

with other chronic illnesses. The sample was in a small geographical area in the Northeast United States, with limited cultural diversity. These parents' experiences may not reflect parents' experiences in other geographical areas or of a more culturally diverse sample. The majority of the participants were mothers ($n = 8$), limiting descriptions of the fathers' experiences to 3 participants. These parents were all married partners, limiting the generalizability to differently-composed families. This is a skewed sample as interviewees may not be representative of entire cohort. These participants agreed to be interviewed. Those who did not respond to contact attempts may have had different experiences with the STEP intervention.

The small sample size limited the quantitative results to description only. In addition, the FaMM was administered at the end of the 12-month intervention. An identified methodological challenge was attrition, which may have affected the validity of the findings. The risk for attrition increases when the length of time between points of data collection is long. The length of the STEP 12-month intervention may have increased the attrition of parents. Attrition may also be influenced by relocation of parents and families. Finally, the order of data collection may have influenced parents' responses. Although all parents were interviewed with the qualitative interview guide, followed by the FaMM instrument, the order of data collection can influence responses (Deshefy-Longhi, Sullivan-Bolyai, & Dixon, 2010).

Conclusions

The findings from the qualitative portion of this study described the experiences of parents of children newly diagnosed with T1DM enrolled in a 12-month formalized social support program. Identified themes of availability, practical tips, and common ground resonated throughout the interviews with parents and reflected Ireys' emotional, informational, and affirmational social support. Formal interviews substantiated the sense of support the parents felt

from the parent mentors, which was not reflected in the significance of the analysis of the quantitative measures used in the STEP RCT. Regardless of the intervention dose, number of parent mentor contacts, or scores on the FaMM scales, all parents when questioned, gave a 5/5 for satisfaction with the STEP RCT, qualitatively underscoring the positive effect of the intervention.

The assessment of patterns of family management in childhood chronic illnesses using the FaMM is ongoing, with cluster analysis recently used to identify six distinct family management styles. The use of the FaMM in this small sample, including assessment of psychometric characteristics, added to the limited literature on its use in parents of children newly diagnosed with T1DM.

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Appendix A

STEP Post-Intervention Interview Guide

- 1) Can you share with me how you came to know your child had diabetes?
- 2) Since the focus of the study was social support, can you tell me what it means to you, how do you describe it?
- 3) Can you share with me a little about the experience of interacting with the parent mentor (PM)?
- 4) How many times has the parent mentor made home visits?
- 5) How often was telephone contact made with the parent mentor?
- 6) Were the number and timing of the visits and calls appropriate?
- 7) Can you tell me what was helpful about the program? What was not helpful?
- 8) On a scale of 1-5 – (5 being the most helpful), how helpful was it?
- 9) What topics did you and the parent mentor discuss?
- 10) What other topics would you recommend they discuss?
- 11) What are your recommendations for how we might improve the program to meet your own specific needs?

Appendix B



FAMILY MANAGEMENT MEASURE

This questionnaire is about how your family manages caring for a child with a chronic condition.

INSTRUCTIONS

For each statement in this questionnaire, you are asked to rate your response to the statement on a scale of 1 to 5, with 1 indicating “Strongly disagree” and 5 indicating “Strongly agree”. Please respond to each statement in this questionnaire based on what you think, not on how you think others might respond. If your child has more than one chronic condition the word “condition” refers to all of their diagnoses together. Also, many of these questions use the word “family”. This refers to those people living in your household who you think of as family.

Section 1: to be completed by everyone
Please check the boxes with your answers.

	Strongly Disagree 1	2	3	4	Strongly Agree 5
1. Our child's everyday life is similar to that of other children his/her age.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Our child's condition gets in the way of family relationships.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Our child's condition requires frequent visits to the clinic.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. In the future we expect our child to take care of the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Our child enjoys life less because of the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Taking care of our child's condition is often overwhelming.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Our child's condition is like a roller coaster with lots of ups and downs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly Disagree				Strongly Agree
	1	2	3	4	5
8. Our child's condition is the most important thing in our family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. It is very hard for us to take care of our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Our child takes part in activities he/she wishes to despite the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Because of the condition, we worry about our child's future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Our child's condition doesn't take a great deal of time to manage.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. We have some definite ideas about how to help our child live with the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Despite the condition, we expect our child to live away from home in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. We have enough money to manage our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Our child is different from other children his/her age because of the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. It is difficult to know when our child's condition must come first in the family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. We are looking forward to a happy future with our child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. When something unexpected happens with our child's condition, we usually know how to handle it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Our child's friendships are different because of the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly Disagree				Strongly Agree
	1	2	3	4	5
21. We expect to be devoting less time to our child's condition in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. A condition like the one our child has makes family life very difficult.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Our child's condition rarely interferes with other family activities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Our child's condition requires frequent hospital stays.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. We feel we are doing a good job taking care of our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. People with our child's condition have a normal length of life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. It's often difficult to know if we need to be more protective of our child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. We often feel unsure about what to do to take care of our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Our child's condition will be harder to take care of in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. We think about our child's condition all the time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. It seems as if our child's condition controls our family life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Many conditions are more serious than our child's.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. It is hard to get anyone else to help us with our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. We have not been able to develop a routine for taking care of our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly Disagree 1	2	3	4	Strongly Agree 5
35. It takes a lot of organization to manage our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. We are sometimes undecided about how to balance the condition and family life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. It is hard to know what to expect of our child's condition in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Even though our child has the condition, we have a normal family life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. Our child would do better in school if he/she didn't have the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. We are confident that we can take care of our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. We have goals in mind to help us manage our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. It is difficult to fit care of our child's condition into our usual family routine.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Dealing with our child's condition makes family life more difficult.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. We know when our child needs to be a child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. A condition like the one our child has makes it very difficult to live a normal life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

This ends Section 1.

Section 2 covers aspects of family management when there are adult partners in a household.

The term "partner" refers to a spouse or partner living in the same household.

Do you have a spouse or adult partner living in your home?

Yes ☐ No ☐

If you currently have a partner living in the same household, please proceed to the next page. If you do not have a partner, please stop here.

Section 2

The questions in the next section relate to you and your partner. For each statement in this section, rate your response to the statement on a scale of 1 to 5, with 1 indicating "Strongly disagree" and 5 indicating "Strongly agree". Again, please respond to each statement in this questionnaire based on how YOU feel, not on how you think your partner or others might respond.

	Strongly Disagree 1	2	3	4	Strongly Agree 5
46. We are a closer family because of how we deal with our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. My partner and I have different ideas about how serious our child's condition is.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. I am pleased with how my partner and I work together to manage our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. My partner and I argue about how to manage our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. My partner and I consult with each other before we make a decision about our child's care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51. My partner and I have similar ideas about how we should be raising our child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52. I am unhappy about the way my partner and I share the management of our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
53. My partner and I support each other in taking care of our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2/16/07

Appendix C

Scoring Instructions for the FaMM

The FaMM questionnaire has two sections. The items from Section 1 are answered by all parents and are used to calculate five scales: Child's Daily Life, Condition Management Ability, Condition Management Effort, Family Life Difficulty, and View of Condition Impact. The items from Section 2 are answered only by parents who have adult partners in the household and are used to calculate a sixth scale: Parental Mutuality. Item numbers are given by the order in which they are listed on the FaMM questionnaire. Reverse coded items are indicated with an asterisk.

Calculation of Scale Scores

Follow these steps to compute the FaMM scales.

1. Determine the number of items in a scale with valid responses (i.e., values of 1-5).
2. Compute a scale score from the valid responses as instructed in steps 3-7, **but only if at least seventy percent of the items for that scale have valid responses** (minimum numbers for the scales are provided below). If less than 70% of the items are answered, the scale cannot be computed.
3. Reverse code the negative item responses (indicated by asterisks) by subtracting those item responses from the value 6.
4. Sum the positive item responses and the reverse coded negative item responses.
5. Divide by the number of valid responses.
6. Multiply by the total number of items for the scale.
7. Round to the nearest integer.

Child's Daily Life Scale

This scale addresses parents' perception of the everyday life of the child. Higher values indicate more normal life for the child despite the condition.

1. Our child's everyday life is similar to that of other children his/her age.
10. Our child takes part in activities he/she wishes to despite the condition.
5. *Our child enjoys life less because of the condition.
16. *Our child is different from other children his/her age because of the condition.
20. *Our child's friendships are different because of the condition.

Total number of items = 5.

Minimum number of valid responses required to compute the scale score = 4.

Condition Management Ability Scale

This scale addresses parents' perception of their ability to manage their child's condition. Higher values indicate that the condition is viewed as more readily manageable.

- 4. In the future we expect our child to take care of the condition.
- 13. We have some definite ideas about how to help our child live with the condition.
- 14. Despite the condition, we expect our child to live away from home in the future.
- 15. We have enough money to manage our child's condition.
- 18. We are looking forward to a happy future for our child.
- 19. When something unexpected happens with our child's condition, we usually know how to handle it.
- 25. We feel we are doing a good job taking care of our child's condition.
- 41. We have goals in mind to help us manage our child's condition.
- 17. *It is difficult to know when our child's condition must come first in our family.
- 27. *It's often difficult to know if we need to be more protective of our child.
- 28. *We often feel unsure about what to do to take care of our child's condition.
- 34. *We have not been able to develop a routine for taking care of our child's condition.

Total number of items = 12.

Minimum number of valid responses required to compute the scale score = 9.

Condition Management Effort Scale

This scale addresses parents' perception of the time and work required to manage their child's condition. Higher values indicate more time and work expended in managing the illness.

- 3. Our child's condition requires frequent visits to the clinic.
- 7. Our child's condition is like a roller coaster with lots of ups and downs.
- 35. It takes a lot of organization to manage our child's condition.
- 12. *Our child's condition doesn't take a great deal of time to manage.

Total number of items = 4.

Minimum number of valid responses required to compute the scale score = 3.

Family Life Difficulty Scale

This scale addresses parents' perception of the extent to which their child's condition makes their life difficult. Higher values indicate more difficulty in dealing with the condition.

- 2. Our child's condition gets in the way of family relationships.
- 6. Taking care of our child's condition is often overwhelming.
- 9. It is very hard for us to take care of our child's condition.
- 22. A condition like the one our child has makes family life very difficult.
- 31. It seems as if our child's condition controls our family life.
- 33. It is hard to get anyone else to help us with our child's condition.
- 36. We are sometimes undecided about how to balance the condition and family life.
- 39. Our child would do better in school if he/she didn't have the condition.
- 42. It is difficult to fit care of our child's condition into our usual family routine.
- 43. Dealing with our child's condition makes family life more difficult.
- 45. A condition like the one our child has makes it very difficult to lead a normal family life.
- 23. *Our child's condition rarely interferes with other family activities.
- 38. *Even though our child has the condition, we have a normal family life.
- 44. *We know when our child needs to be a child.

Total number of items = 14.

Minimum number of valid responses required to compute the scale score = 10.

Parental Mutuality Scale

This scale is calculated from the items in Section 2 of the FaMM questionnaire, answered only by parents with an adult partner living in the home. It addresses parents' satisfaction with how the couple works together to manage their child's condition and their perception of the degree to which they receive support from their partner and share views on the management of their child's condition. Higher values indicate that the condition is viewed as more readily manageable.

- 46. We are a closer family because of how we deal with our child's condition.
- 48. I am pleased with how my partner and I work together to manage our child's condition.
- 50. My partner and I consult with each other before we make a decision about our child's care.
- 51. My partner and I have similar ideas about how we should be raising our child.
- 53. My partner and I support each other in taking care of our child's condition.
- 47. *My partner and I have different ideas about how serious our child's condition is.
- 49. *My partner and I argue about how to manage our child's condition.
- 52. *I am unhappy about the way my partner and I share the management of our child's condition.

Total number of items = 8.

Minimum number of valid responses required to compute the scale score = 6

View of Condition Impact Scale

This scale addresses parents' perception of the seriousness of the condition and its implications for the future. Higher values indicate a higher level of concern about the condition.

- 8. Our child's condition is the most important thing in our family.
- 11. Because of the condition, we worry about our child's future.
- 24. Our child's condition requires frequent hospital stays.
- 29. Our child's condition will be harder to take care of in the future.
- 30. We think about our child's condition all the time.
- 37. It is hard to know what to expect of our child's condition in the future.
- 21. *We expect to be devoting less time to our child's condition in the future.
- 26. *People with our child's condition have a normal length of life.
- 32. *Many conditions are more serious than our child's.
- 40. *We are confident that we can take care of our child's condition.

Total number of items = 10.

Minimum number of valid responses required to compute the scale score = 7.

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