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Educating Grandparents of Grandchildren with Type I Diabetes Using Simulation: A Dissertation

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Educating Grandparents of Grandchildren with Type I Diabetes Using Simulation

A Dissertation Presented

By

Laura L. Maguire

Submitted to the Graduate School of Nursing
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In partial fulfillment of the requirements for the degree of

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Graduate School of Nursing

Educating Grandparents of Grandchildren with Type 1 Diabetes Using Simulation

A Dissertation Presented

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Abstract

The purpose of this study was to explore the feasibility of using human patient simulation (HPS) to teach Type 1 diabetes (T1DM) management to grandparents of grandchildren with T1DM. Thirty grandparents (11 male, 19 female) of young grandchildren (aged 12 and under) with T1DM were recruited from an urban medical center. Experimental group ($n = 14$) grandparents received hands-on visual T1DM management education using an HPS intervention, and control group ($n = 16$) grandparents received similar education using a non-HPS intervention. Post-intervention, researchers interviewed twelve grandparents (50% HPS, 50% non-HPS) who scored highest and lowest on the Hypoglycemia Fear Survey. Using a mixed-method design, researchers integrated study instrument data and post-intervention interview data to describe grandparent's experience learning T1DM management.

Post-intervention, grandparent scores for knowledge, confidence, and fear showed no significant difference by group assignment, however, all grandparent scores showed improvement from Time 1 to Time 2. Grandparents described how taking part in T1DM education heightened their awareness of T1DM risks. GP T1DM knowledge gains aided GPs to make sense of T1DM risks. Newfound T1DM knowledge enhanced GP T1DM management confidence. Improved T1DM knowledge and confidence helped to defuse T1DM management fear. Although study instruments did not measure significant difference between grandparents who received the HPS intervention and those who did not, the consistency of larger HPS-taught grandparent score improvement is suggestive of a benefit for HPS

Key words: Type 1 Diabetes Mellitus, patient simulation, patient education, family caregivers, grandparents, T1DM management and support, HPS education, mixed-methods

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Introduction

Type 1 Diabetes Mellitus (T1D), the leading childhood metabolic disorder, affects nearly 1 in 400 children and adolescents (American Diabetes Association, 2013). T1DM incidence in young children is increasing, potentially doubling the burden of this disease by 2020 (Patterson et al., 2009; Vehik & Dabelea, 2011). The diagnosis of T1DM in a young child affects the entire family (Anderson, Loughlin, Goldberg, & Laffel, 2001; Lowes, Gregory, & Lyne, 2005). Parents have reported a lack of secondary caregiver support due to the complexity of their children's' T1DM management (Ginsburg et al., 2005; Hoff et al., 2005; Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2003; Smaldone & Ritholz, 2012).

Grandparent-provided childcare (i.e., babysitting, disease management, and respite) is an important source of caregiving support for parents raising children with chronic health conditions (CHCs) (Lee & Gardner, 2010; Mitchell, 2007). Declining U.S. mortality rates have increased availability of grandparent caregivers (Hoff et al., 2005; Spence, Black, Adams, & Crowther, 2001). Increased teen birth rates and delayed childbearing among older females have widened the age range of grandparent caregivers (Hooyman & Kiyak, 2008). According to 2011 U.S. Census data, 32% of children under age five with working mothers are regularly cared for by a grandparent during mother's working hours (Laughlin, 2013).

Grandparents are a vital source of caregiver support for parents with children having CHCs such as autism (Margetts, LeCouteur, & Croom, 2006), neurologic conditions (Green, 2001; Katz & Kessel, 2002), heart disease (Ravindran & Rempel, 2010) and disabilities (Lee & Gardner, 2010). However, no previous research was found explicitly examining how grandparents support their adult children parenting a child with T1DM. In one qualitative study describing maternal perspectives of raising a child with T1DM, mothers reported that their

parents (who previously babysat pre-T1DM diagnosis) became too fearful to continue babysitting for their grandchild post- diagnosis (Sullivan-Bolyai, Deatrick et al., 2003). Although it has been implicitly reported that grandparents may be involved in their grandchildren's T1DM management (De Oliveira, Nascif-Junior, & Rocha, 2010), little is known about their experiences, concerns, level of involvement, or how they learned T1DM care.

Parents coordinate their children's daily caregiving, and typically, parents also assume responsibility for teaching T1DM management to secondary caregivers, including grandparents (McDougal, 2002). This teaching includes knowledge and skills in: (a) monitoring blood glucose; (b) administering insulin; (c) monitoring physical activity; (d) ensuring healthy eating; and (e) recognizing, preventing and treating hypo/hyperglycemia (Lowes, Lyne, & Gregory, 2004; Silverstein et al., 2005; Sullivan-Bolyai, Knafl, Deatrick & Grey, 2003.

U.S. National Standards of Diabetes Self-Management Education and Support (DSMES) define the knowledge, problem-solving, and coping skills that certified diabetes educators (CDEs) must include when teaching T1DM management to patients and families (Haas et al., 2013). Ideally, DSMES certified healthcare professionals, rather than parents, should be delivering grandparent T1DM management educational interventions (Funnell, 2008).

Innovative Model of Parent T1DM Education using Human Patient Simulation (HPS)

For nearly a decade, HPS has been used to teach nursing and medical students nuances of patient care, including psychomotor and decision-making skills (Jeffries, 2005; Morgan, Cleave, Hogg, DeSousa, & Tarshis, 2004; Wright et al., 2005). Parent Education through Simulation-Diabetes (PETS-D; NINR: 1RO1NR011317, in progress) is an innovative parent education intervention using HPS. Presently, PETS-D is being tested for efficacy in teaching T1DM management to parents whose children are newly diagnosed. The PETS-D intervention offers 3

existing teaching vignettes, addressing: (a) hypoglycemia management; (b) hyperglycemia management; and (c) pattern recognition that includes nutrition, activity, and sick day management. To date, it has not been tested with grandparents. However, the PI recently conducted a focus group study to explore grandparents' perspectives regarding their experiences with T1DM, learning T1DM management, and using HPS.

Specific Aims

The purpose of this feasibility study is to adapt an existing HPS intervention (PETS-D) for teaching hypoglycemia management to grandparents of young children (aged 12 and younger) with T1DM. Findings from this study will provide preliminary data to inform a future powered RCT addressing grandparent's comprehensive T1DM management needs. The specific aims are to:

Aim 1. Explore the feasibility of implementing the HPS intervention (using Self-Regulation framework) to teach hypoglycemia episode management to grandparents and to specifically:

- Explore recruitment and retention issues
- Compare preliminary differences (mean within-person change) between the experimental and control groups for grandparent functional response (diabetes knowledge, hours of unassisted care provided, and T1DM management) and grandparent emotional response (fear of hypoglycemia, self-efficacy).
- Develop and test an intervention fidelity plan (IFP)

Aim 2. Explore grandparent learning experiences (including receptivity to HPS) and perceived participant burden across experimental and control groups through semi-structured focused qualitative interviews.

Background and Significance

T1DM results from an autoimmune process that destroys insulin-producing pancreatic beta cells eventually leading to a total loss of endogenous insulin production. Insulin is a hormone that regulates the body's blood glucose levels. To survive, people with T1DM must have exogenous insulin delivered by multi-dose injection or a continuous pump. Risk factors for T1DM may be autoimmune, genetic, or environmental and there is no known way to prevent T1DM (CDC, 2011). T1DM is a leading cause of coronary and peripheral vascular disease, retinopathy, nephropathy, and neuropathy, (Mayer-Davis et al., 2009). T1DM also contributes to depression, pregnancy complications, and acute life-threatening events such as diabetic ketoacidosis and hypoglycemia (CDC, 2011). Patients with diabetes have twice the risk of myocardial infarction, stroke, and death as that of the general population (Buse et al., 2007; CDC, 2011).

T1DM incidence in all age groups is reported to be increasing by 2–5% worldwide (Lipman et al., 2013; Vehik & Dabelea, 2011). T1DM onset can occur at any age, yet is more common in children and young adults (Dabelea et al., 2007; Patterson et al., 2009) with 75% of all cases diagnosed in children under 18 years old (ADA, 2013). T1DM prevalence has been reported as approximately 1 of every of 400 U.S. youth aged 0-19 years (ADA, 2013). In 2009, an estimated 166,984 U.S. youth (age 0-19) were living with T1DM (Pettitt et al., 2013). Researchers from the SEARCH study, a U.S. multicenter observational population-based study of T1DM among youth (age 0-19; $N = 3,458,974$), estimated a 23 % increase in prevalent cases of T1DM (1.93/1000) between 2001-2009 (JDRF, 2013; Mayer-Davis et al., 2009).

Grandparent Caregiving of Grandchildren: An Important Source of Support

The frequency of grandchild-grandparent contact has been found to be positively

associated with grandparent life satisfaction (Goodman & Silverstein, 2001; Ku et al., 2013) and

with grandchild-grandparent relationship closeness (Davey, Savla, Janke, & Anderson, 2009).

Several factors have been reported to influence the level of involvement that grandparents have

in their grandchild's daily caregiving, including: (a), residential proximity (Lee & Gardner,

2010; Park, Hogan, & D'Ottavi, 2004), (b) closeness of grandparent and middle generation

(grandchildren's parents) relationship (De Oliveira, Nascif-Júnior, & Rocha, 2010; Katz &

Kessel, 2002; Margetts, Le Couteur, & Croom, 2006), and (c) grandparent capacity to provide

functional and emotional support (Luo, LaPierre, Hughes, & Waite, 2012; Winefield & Air,

2010).

Longitudinal data from a nationally representative sample of grandparents ($N = 13,626$)

who participated in a Health and Retirement Study from 1998-2008 revealed that more than 60%

of grandparents interviewed provided grandchild care over a 10-year period, with more than 70%

of those providing care, doing so for 2 years or more (Luo, LaPierre, Hughes, & Waite, 2012).

Another cross-sectional survey administered to international college students ($N = 70$)

studying in the United States examined grandchildren's perspectives on their relationship with

their grandparents. Grandchild perception of their closest grandparent as [functional] mentor ($\beta =$

.14, $p < .10$) and [emotional] nurturer ($\beta = .47, p < .01$) was a significant predictor of

intergenerational relationship satisfaction (Taylor, Robila, & Lee, 2005).

Dunifon and Bajracharya (2012) conducted a secondary analysis of telephone interview

data from the second wave (1992-1994) of the National Survey of Families and Households ($N =$

551 youth aged 14-19) to examine predictors of grandparent-grandchild relationship quality. These researchers reported that a one-point increase in parent-grandparent relationship quality (0 = bad to 10 = perfect) was associated with a 13% *S.D.* increase in the grandparent-grandchild relationship quality composite score (0 = least close to 10 = extremely close). These findings suggest the presence of a parental gate-keeping role within the grandparent-grandchild relationship, similar to findings previously reported by Mueller and Elder (2003).

Grandparent caregiving of a grandchild diagnosed with a CHC. Grandparents provide functional and emotional support for parents caring for children with CHCs (Hastings, Thomas, & Delwiche, 2002; Katz & Kessel, 2002; Lee & Gardner, 2010; Margetts, LeCouteur, & Croom, 2006; Mitchell, 2007, 2008). Grandparent caregiving is positively associated with maternal (Heller Hsieh, & Rowitz, 2000) and parental (Green, 2001; Trute, 2003) functional and emotional well-being. Katz and Kessel (2002) interviewed grandparents (*N* = 16) of children diagnosed with developmental disabilities reporting that grandparents viewed their role grandparenting a grandchild with disability as rewarding. In addition, these grandparents wished to provide greater emotional and instrumental support to their children and grandchildren.

Despite holding valued roles supporting families of children with CHCs, grandparents receive inadequate functional (Findler, 2008; Heller, Hsieh, Rowitz, 2000) and emotional support (Lee & Gardner, 2010; Mitchell, Clarke, & Sloper, 2005) from the grandchild's healthcare providers. Resultant knowledge deficits regarding their grandchild's CHC may add to parental burden (Lee & Gardner, 2010; Trute, 2003). Green (2001) reported an inverse relationship between a grandparent's functional involvement caring for their disabled grandchild and the parent's perception of having to manage grandparent emotional response understanding

the child's CHC. In other words, parents experienced more negative feelings interacting with their child's grandparents when grandparents were less involved in the child's care.

Functional Response and Grandparent Management of Grandchildren with CHCs.

Despite grandparents being described as the most important source of secondary caregiving for parents of children with CHCs (Lee & Gardner, 2010; Mitchell, 2008), the functional response literature has limited empirical information as to how grandparents learn to manage their grandchild's CHC. Two studies explored grandparent involvement in family functioning (Green, 2001; Hastings, Thomas, and Delwiche, 2002). The first, a two-phased mixed method study examined the relationship between grandparent caregiving and parental well-being (Green, 2001). Parents ($N = 91$) from three clinics serving children with CHCs were surveyed, then individually ($n = 7$) interviewed. According to Greene, grandparent(s) provided functional assistance with routine caregiving tasks at least once weekly in 41% of families. In other words, parents were more likely to receive weekly help provided by grandparents, than they were from other relatives (27 % of families; $t = 2.47$, $p = < .05$) or from friends (20 % of families; $t = 3.39$, $p = <.01$). In this study, weekly grandparent help was significantly related to parents' maintaining a positive emotional outlook and avoiding exhaustion ($\beta = .35$, $p = <.05$).

Hastings and colleagues (2002) surveyed parents of children with Down's syndrome ($N = 61$) to exam the relationship between parental stress and grandparent support. They reported that grandparent caregiving was inversely associated with maternal report of stress ($r = -0.41$, $p = .05$) indicating that greater grandparent involvement was associated with lower maternal stress.

Emotional Response and Grandparent Management of Grandchildren with CHCs.

Similar to functional response empirical literature, the emotional response literature is primarily qualitative with small samples. Nevertheless, some important findings can be gleaned to support

the PI's proposed study. When a grandchild is diagnosed with a CHC, grandparent emotional responses may mirror parents' responses (Gardner & Scherman, 1994; Vadasy, Fewell, & Meyer, 1986). Interviews conducted with grandparents of grandchildren with autism ($N = 6$) reported emotional fear and loss of confidence related to their grandchild's diagnosis (Margetts, Le Couteur, & Croom, 2006). Grandparent understanding of and emotional response to, their grandchild's CHC is an important, yet overlooked, factor influencing their functional response to supporting their own children and grandchildren (Lee & Gardner, 2011; Mitchell et al., 2005).

Several qualitative studies have described how a grandparent's emotional concern is compounded when a grandchild is diagnosed with a CHC. Vadasy, Fewell and Meyer (1986) asked grandparents of young children diagnosed with handicaps ($N = 21$) a series of open-ended questions. Grandparents reported experiencing a two-fold emotional response to their grandchild's diagnosis. First, feeling concern and worry for their adult child and subsequently experiencing a "double grief" concerning their grandchild (p. 36). In a phenomenological study of grandmothers of critically ill children ($N = 7$), Hall (2004) also described the "double concern" of grandparent; worrying first for the parents and then again for the grandchild (p. 63). Likewise, in the PI's preliminary focus groups (see Innovative Model of Grandparent T1DM Education using HPS section), grandparents reported similar twofold emotional response, which subsequently shaped their functional and emotional response to supporting their adult child, as well as their grandchild diagnosed with T1DM. Most recently, Ravindran and Rempel (2010) reported a three-fold emotional concern for grandparents of preschool children diagnosed with congenital heart disease ($N = 15$): first for their adult children, second for their grandchild with heart disease, and third, for siblings of their sick grandchild.

Grandparent involvement in T1DM day-to-day management and T1DM education

Most young children with T1DM, age 12 & under, live with parents who typically assume major responsibility for their care. Multiple aspects of childhood T1DM day-to-day management are stressful due to a young child's small insulin adjustments, transient food preferences, resistance to painful glucose testing, and developmentally limited communication skill (Powers et al., 2002). Caring for a grandchild with T1DM requires a caregiver learn a variety of functional skills, such as glucose monitoring and administering medication injections.

De Oliviera and colleagues (2010), conducted case study research with families of children with T1DM ($n = 4$) examining family characteristics and resources. This study implicitly identified grandparents as potential sources of instrumental and emotional support. Factors that influence the degree to which grandparents are involved in their grandchild's T1DM management have not yet been described. Additionally, no studies could be found that specifically described grandparent activities when caring for their grandchildren with T1DM. Furthermore, no studies could be found that explored the development of teaching interventions for grandparents wanting to learn T1DM care or support their adult children and grandchild affected by T1DM.

Fear of hypoglycemia is a common fear for parents of a child with T1DM (Barnard, Thomas, Royle, Noyes, Waugh, 2010; Lowes et al., 2005; Sullivan-Bolyai, Deatrick, et al., 2003; Sullivan-Bolyai, Knafl et al., 2003). Likewise, in the PI's preliminary study, grandparents reported that T1DM management, especially hypoglycemia, can be daunting and was typically taught informally by their adult children. Sullivan-Bolyai, Deatrick, and colleagues (2003) conducted a mixed method study describing the day-to-day experiences of mothers ($N = 28$) raising young children with T1DM. These researchers reported that grandparents, who

previously had babysat, became too fearful to care for the child post-T1DM diagnosis. Smaldone and Ritholz (2011) interviewed parents of young children with T1DM (N = 14) similarly reporting a fearful hesitancy among grandparents about independently managing their grandchild's T1DM care.

Innovative Model of Grandparent T1DM Education using HPS

It is not known if providing grandparents concrete information using HPS can increase their knowledge and confidence when providing T1DM management, thereby decreasing their fear of providing care. For nearly a decade, HPS has been reported to enhance the learning process (Jeffries, 2005; Morgan et al., 2004; Wright et al., 2005; Vozenilek et al., 2004). One RCT of HPS-taught medical students (N = 90) reported a small to moderate effect (Cohen's d, 0.36) between group change, with improved knowledge, skills, test scores, and satisfaction (Ten Eyck, Tews, & Ballester, 2009). Sullivan-Bolyai, Crawford, and colleagues (2012) conducted a feasibility study with a small sample of camp counselors (N = 38) to test HPS hypoglycemia management teaching. These researchers demonstrated significant gain in short-term knowledge in an HPS group (n = 21) who had no previous experience with T1DM management (M = 1.24, p = .001) compared to a non-HPS group (n = 15) (M = .58, p = .001).

Two pilot studies recently evaluated using HPS to teach parents hypoglycemia management for their children diagnosed with T1DM (Sullivan-Bolyai, Bova, Lee & Johnson, 2012). The first single-group pilot study (N =10) found the educator and participants receptive to HPS teaching. The second two-group pilot study (N =16) found similar positive receptivity from parents, as well as preliminary mean changes from baseline to post intervention in the predicted direction for all measures administered. For instance, mean diabetes knowledge scores increased in the HPS experimental group from 62 to 78 compared to the comparison group mean score

decrease from 61 to 51. A fully powered RCT is presently testing this intervention with parents of children newly diagnosed with T1DM.

The PI conducted a preliminary focus group study to explore using HPS to teach grandparents T1DM management. During focus groups, a snippet of the PETS-D HPS hypoglycemia management vignette was demonstrated. Study sample ($N = 19$, $M = 69$ years, $SD = 7$; 8 male/11 female) included one grandparent group active in their grandchildren's T1DM management ($n = 11$, 5 male/6 female) and one grandparent group who were not ($n = 8$, 3 male/5 female). Grandparents reported: (a) that the complexity of T1DM management, especially hypoglycemia management, was daunting; (b) that their adult children were largely responsible for providing their T1DM education; (c) receptivity to learning with HPS; and (d) their recommendations for adapting to the PETS-D intervention. Grandparent recommendations to supplement written materials, focus on hypoglycemia management focus, and deliver the intervention 2 months post-diagnosis were incorporated into this study proposal

This proposed study will be the first to explore delivering one segment (hypoglycemia) of the 3 PETS-D teaching sessions for feasibility including recruitment, retention, and IFP. The single session intervention will include basic T1DM written preparatory materials, didactic overview of T1DM by a nurse CDE, and hands-on visual practice of hypoglycemia management performed using HPS. Data from this proposed study will provide the groundwork for developing a more comprehensive powered grandparent education intervention including other aspects of diabetes management such as sick-day management, nutrition, and exercise.

Summary

Previous research has suggested that grandparents do desire to support their children who are parenting a child with a CHC, including T1DM. Yet, despite their potential value providing

secondary caregiving to grandchildren with T1DM, grandparents have received little explicit research attention. Prior to the PIs preliminary study, no research had specifically examined the concerns, or level of involvement, of grandparents of grandchildren with T1DM. Additionally, no studies have reported how fearful or confident grandparents are if left with their grandchild's T1DM management. Similar to concerns expressed by parents, the fear of hypoglycemia may potentially threaten a grandparent caregiver's functional and emotional response to T1DM management.

Research specifically exploring grandparent caregiving in families of children with CHCs is needed for the effective development of interventions that address overlooked needs in grandparent caregiver education (Hastings, Thomas & Delwiche, 2002; Findler, 2008; Heller, Hsieh, & Rowitz, 2000; Lee & Gardner, 2010; Mitchell et al., 2005; Mitchell, 2008; Reichman, Corman, & Noonan, 2008; Trute, 2003). The lack of empirical research describing grandparent caregiving for grandchildren with T1DM underscores the significant need for this area of research.

Grandparent study samples have been small, and no interventions could be located that tested differences between T1DM management education strategies conducted with grandparent populations. The abundance of U.S. T1DM research and clinical practice effort is focused toward parent teaching, excluding secondary caregivers. This exclusionary approach may limit parental comfort with relinquishing their child's T1DM management responsibility to others. Findings from this proposed study have the potential to increase much needed parental caregiving support (McDougal, 2002).

A Nurse CDE led hands-on visual educational intervention, such as that provided with HPS education has been reported to enhance learning by reducing fear (Johnson, 1999; Sullivan-

Bolyai, Bova et al., 2012). This suggests the potential value of using HPS to augment grandparent T1DM knowledge and skill development. However, it is not yet known whether providing HPS teaching to grandparents can regulate their emotional response to T1DM management thereby enhancing the functional support they provide to adult children and grandchildren.

Conceptual Framework

This proposed study will explore whether providing grandparents with concrete information using HPS can increase their knowledge and confidence when providing T1DM management, thereby allowing grandparents to better control their fear of providing T1DM care. Johnson's (1999) interpretation of Leventhal's (1970) Self-Regulation Theory (SRT) guided this feasibility study's design, organization, and its intervention. The development of the PETS-D intervention, which is being partially replicated in the dissertation, was also guided by Johnson's (1999) interpretation of Leventhal's (1970) SRT. The SRT framework depicts a model of responding to healthcare events via two coping response pathways: a functional response and emotional response pathway that are interrelated. The SRT functional and emotional response conceptual framework undergirds this proposed study's literature review, and data collection and analysis (see Figure 1). Self-regulation is a process through which people may respond to stressful healthcare events, such as a grandchild's T1DM diagnosis, via two coping response pathways; a functional pathway to achieve functional goals and an emotional pathway to achieve emotional goals (Thoolen, de Ridder, Bensing Gorter, & Rutten, 2008). According to Johnson (1999), SRT is guided by four assumptions regulating the responses and behaviors of persons experiencing a stressful healthcare event. In the context of this proposal, the first assumption of SRT is based upon the grandparents' initial impression of their grandchild's T1DM diagnosis.

Grandparents draw upon their pre-existing perception and interpretation of T1DM knowledge when regulating their response and behavior to managing T1DM.

Figure 1. Study Variables guided by Self-Regulation Conceptual Framework

Functional Response Measures
- # hours of unassisted care provided pre-post intervention
- Diabetes Knowledge (DART-GP)
- Day-to-Day management function (6 FaMM Subscales)

  *Child's daily life   *Management effort
  *Management ability *Family life difficulty
  *Mutuality   *View of the child

- Qualitative interviews (functional response perspectives & receptivity)

Adapt **PETS-D** using grandparent focus group data

Feasibility exploring recruitment, retention, and HPS teaching with Grandparents ($N = 30$)

Emotional Response Measures
- Self-efficacy (SED-GP)
- Fear of hypoglycemia (HFS-GP)
- Qualitative interviews (emotional response perspectives & receptivity)

Second, SRT proposes that grandparents who receive T1DM knowledge via a hands-on visual T1DM education intervention (using HPS) will develop clear objective concrete cognitive images (schemata) that allow them to better control their emotional fear reaction to their grandchild's T1DM diagnosis. Clear concrete schemata development will aid grandparents to develop confidence in their abilities to handle the real-life management of their grandchild's hypoglycemia - if, and when it occurs. Grandparent development of clear concrete schemata will influence what T1DM signs or sensations they look for, what T1DM management actions they take, and what consequences they will anticipate to result from their actions.

A third assumption of SRT is that schemata are organized along a continuum spanning from a simpler concrete level to an increasingly complex abstract one. The organizational level is

hierarchical, with simpler concrete task completion forming the groundwork for more complex abstract problem solving. For example, a grandparent learning to administer insulin is a low-level concrete task; while a grandparent understanding how to assess their grandchild's need for glucagon administration is a high-level abstract undertaking. In this proposed study, the experimental group (*n* = up to 15) receives preparatory hands-on visual (HPS) information of what to expect and how best to respond to hypoglycemia, and the control group (*n* = up to 15) receives similar education without HPS.

Johnson (1999) described how "patients will elect to cope in ways that are consistent with their understanding of the experience" (p. 437). The fourth and final assumption of SRT proposes that grandparents receiving preparatory hands-on visual (HPS) teaching will experience fewer discrepancies between their expectations and their reality, thereby increasing T1DM management confidence and decreasing their T1DM management fear.

Numerous studies have used SRT to adapt educational interventions to benefit patients experiencing a wide range of health care events (Allard, 2007; Clark, Gong, & Kaciroti, 2001; Johnson, Kirchoff, & Endress, 1975; Melnyk, Crean, Feinstein, & Fairbanks, 2008; Thoolen, de Ridder, Bensing, Gorter, & Rutten, 2008). Johnson and colleagues' (1975) seminal RCT pediatric cast removal study laid the groundwork for pre-operative and pre-procedural education in pediatrics. Johnson's three-group experimental study tested children aged 6 to 11 years (*N* = 84) for signs of distress resulting from discrepancies between their expected and their experienced physical sensations during an orthopedic cast removal.

Clark, Gong, and Kaciroti (2001) conducted a 5-year longitudinal study involving serial interviews with care-taking parents of children (aged 1-12 years) with asthma (*N* = 637). This study measured the stability and predictive ability of a chronic disease management model

developed using elements of self-regulation theory (e.g. making judgments based on objective observation versus subjective fear). Their findings supported reasonable stability and predictive ability of self-regulation elements in their model.

More recently, Melnyk and colleagues (2008) conducted a secondary analysis using data from an RCT with mothers ($N = 246$) of low-birth-weight preterm infants, in which mothers were assigned randomly to the Creating Opportunities for Parent Empowerment (COPE) educational-behavioral intervention (guided by Johnson's interpretation of SRT) or a placebo control condition. In this study, researchers examined the processes through which COPE participation influenced maternal anxiety and depression post-premature infant discharge. These researchers reported that the educational-behavioral intervention (COPE) supported SRT concepts by directly influencing maternal cognitive beliefs (schema) and mediating maternal emotional adjustment thereby indirectly reduce maternal stress and anxiety.

Methods

This proposed study focuses on providing hypoglycemia management teaching using HPS to enhance grandparent functional response (diabetes knowledge, number of care hours provided, and day-to-day management functioning) and emotional response (self-efficacy and fear of hypoglycemia) compared to grandparents receiving comparison hypoglycemia management teaching without HPS.

In this feasibility study, the 3-session PETS-D T1DM parent teaching intervention is adapted to a single session hypoglycemia management teaching intervention. The purpose for adapting the PETS-D intervention to a single session hypoglycemia vignette is to explore the feasibility of using HPS with grandparent T1DM education, rather than for testing intervention

efficacy. Focus group data (collected October 2012) described grandparent T1DM learning preferences and informed our adaptations to the PETS-D intervention (see Figure 2).

Figure 2. Sequencing and Sample Size for Grandparent Feasibility Study

Deliver adapted PETS-D teaching intervention to GPs	**Aim 1: Feasibility RCT (N = up to 30)** (n = up to **15** HPS-experimental group GPs) (n = up to **15** non-HPS-control group GPs) ▪ Explore recruitment, retention, refusals ▪ Compare preliminary outcome differences (functional and emotional) ▪ Conduct IFP	**Aim 2: Qualitative Interviews** (n = up to **15** HPS-experimental group GPs) (n = up to **15** non-HPS control group GPs) ▪ Examine GP learning experience ▪ Assess perceived participant burden

The feasibility of grandparent adapted HPS teaching will be explored in this two-group randomized control trial (RCT) (Aim 1). An experimental (HPS) group and a control (non-HPS) group are used to explore recruitment & retention, instrument completion time, participant willingness to be randomly assigned, to examine HPS vs. non-HPS teaching and an IFP (Aim 1). Qualitative interviews examine learning experience and perceived participant burden from both groups (Aim 2).

This study will obtain preliminary estimates of standard deviation indicating the direction & amplitude of the differences between group arms, not to estimate effect size. Thus, sample size is not calculated to achieve statistical power. Thirty subjects are adequate for estimating standard deviation in pilot studies (Lancaster, Dodd, & Williamson, 2004). Feasibility studies are conducted prior to large-scale intervention studies to determine study components and estimate parameters used in designing future powered RCTs, enhancing likelihood of success (Eldridge & Kerry, 2012; Thabane et al., 2010).

Sample

University of Massachusetts Memorial Healthcare **(**UMMHC**)** pediatric diabetes clinicians approach families of patients with T1DM inviting study participation. Parents active in the University of Massachusetts (UMASS) Family Diabetes Network (a family organization supporting parents of children with diabetes) also announce the study to members. Similar procedures readily recruited 19 grandparents for preliminary focus groups. Partnered grandparents are both invited, yet both need not participate. Each grandparent is counted as an individual participant. No interaction with the grandchild or their medical record takes place. A maximum of thirty grandparent participants (up to 15 HPS/up to15 non-HPS) are proposed for this study understanding that power calculation need not be undertaken for feasibility exploration (Arain, Campbell, Cooper, & Lancaster, 2010; Leon, Davis, & Kraemer, 2011).

Inclusion Criteria. Grandparent inclusion criteria are: (a) Grandparent to grandchild aged 12 or under, having T1DM greater than 2 months (focus group recommendation), (b) history of babysitting for the grandchild with T1DM prior to diagnosis, (c) able to communicate in English, and (d) able to provide informed consent**.** It is expected that grandparents who self-initiate phone contact, verbalize informed consent, and attend baseline data collection, will demonstrate (to the PI) through their actions that they are cognitively and functionally intact. Grandchild age (12 & under) was selected because children age 13 and older share greater responsibility for T1DM self-management. Presently, for this internally funded study, including grandparents able to communicate in English is appropriate to study HPS feasibility. Future externally funded HPS intervention studies would hire interpreters to include non-English communicating grandparents.

Exclusion Criteria. The study exclusion criteria are: (a) age 21 years and under; (b) having a grandchild with T1DM along with serious co-morbidity restricting grandparent care; and (c) having T1DM, or actively managing another's T1DM (limiting knowledge/skill bias).

Setting

The study setting is UMMHC, a private non-profit healthcare organization in Worcester, Massachusetts, which consists of two tertiary care centers, an ambulatory surgical center, four full-member hospitals, with affiliated hospitals across Massachusetts. The UMMHC Children's Medical Center provides the only American Diabetes Association-approved program for children in Central Massachusetts. The Pediatric Endocrinology (Pedi Endo) Clinic at the UMMHC Children's Medical Center Diabetes Center of Excellence provides care for infants, children, and adolescents with type 1 and type 2 diabetes. Pediatric endocrinologists, certified diabetes nurse educators, dieticians, social workers, child life specialists, and psychologists staff the Pedi Endo clinic. The UMMHC multi-disciplinary team offers initial treatment and education of the child newly diagnosed with diabetes, outpatient management, consultative services, meal planning and nutritional assessments, self-management classes, behavior change strategies, family assessments, and social services.

According to March 2014 CDE log, UMMHC Pedi Endo providers care for a total population ($N = 398$) of children aged 17 and under with T1DM. This proposed study will recruit from 34.9 % ($n = 139$) of the total clinic population, excluding children aged 13 and older. According to UMMHC Pedi Endo CDE log, the race/ethnicity breakdown for all new clinic patients (age 17 and under) with T1DM ($N = 61$) from January to December 2014 was 82 % ($n = 50$) Caucasian, 8.2 % ($n = 5$) Hispanic, 4.9 % ($n = 3$) Black, 1.6 % ($n = 1$) Black/Caucasian, 1.6 % ($n = 1$) Hispanic/Caucasian, 0 % ($n = 0$) Asian, and 1.6 % ($n = 1$) missing race/ethnicity data.

Measures

Demographic Data Form. Demographic data will include grandparent age, presently and at onset of grandparenthood, gender, education, ethnicity, race, residence, and marital and employment status, number of grandchildren, hours of grandchild caregiving, age of grandchild with T1DM, and grandparent T1DM management experience (see Appendix A).

Diabetes Awareness and Reasoning Test - Grandparent (DART-GP). This 38-item modified (eliminating insulin-specific questions) multiple-choice questionnaire (see Appendix B) measuring diabetes knowledge utilizing 4 response options (Sullivan-Bolyai, Bova, Lee, and Johnson, 2012) was adapted from the original 47-item DART (Heidgerken et al., 2007). Sullivan-Bolyai, Bova and colleagues (2012) reported Alpha for this modified scale as 0.97.

Family Management Measure – Grandparent (FaMM). This 53-item instrument (Knafl et al., 2009) featuring a 5-point likert scale (see Appendix C) was developed from five summated scales (45 items) for all participants, measuring the dimensions of Child's Daily Life, Condition Management Ability, Condition Management Effort, Family Life Difficulty, and View of Condition Impact, as well as one additional 8-item 5-point likert scale measuring the dimension of Mutuality for partnered participants only. When administered to parents of children with T1DM, Rearick and colleagues (2011) reported Cronbach alpha for five of six FaMM scales as: CDL (.80), CMA (.86), FDL (.90), VCI (.83), & PM (.91). One scale, CME, had a low alpha at .50, thus we will carefully examine reliability of the CME with our population.

Self-Efficacy Diabetes – Grandparent (SED-GP). This 22-item 5-point likert scale (see Appendix D) measures self-efficacy, including confidence, in managing specific tasks and skills associated diabetes care (e.g.. how confident one feels to perform day-to-day diabetes

management) (Grossman, Brink, & Hauser, 1987). Streisand and colleagues (2005) reported SED-P total scale Cronbach alpha of .87 with parents of children with T1DM**.**

Hypoglycemia Fear Survey (HFS-GP). This 27-item 5-point likert scale (see Appendix E), with two subscales measures concern for the child experiencing an episode of hypoglycemia and behaviors used to prevent these episodes from occurring (Clarke, Gonder-Frederick, Snyder, & Cox, 1998). Sullivan-Bolyai, Bova, and colleagues (2012) reported total scale alpha of .85 -.93 in pilot testing with parents of children with T1DM.

Qualitative Interview Guide. Purposively selected grandparents (see Figure 3) will be invited to participate in a qualitative phone interview (Time 3). Time 3 qualitative data are collected using focused semi-structured open-ended questions (see Appendix F).

Data Collection

Figure 3 depicts the sequence of data collection for the proposed study. The functional response measures (DART-GP & FaMM) and emotional response measures (SED-GP & HFS-GP) were originally developed for use with parents and their children**.** Item wording of all instruments have been modified by replacing the word *parents* with *grandparents,* and the word *child* with *grandchild.* Internal consistency reliability (Cronbach's Alpha) of all measures will be calculated in this sample.

Procedures

UMMS IRB approval will be obtained. Figure 3 depicts recruitment, enrollment, and data collection procedures for the proposed study. Participant enrollment will continue until up to 30 participants have consented to enrollment in the study. Post-intervention qualitative interviews will continue until informational redundancy occurs. Financial incentives are offered to cover cost of transportation, for appreciation for time spent, and to encourage retention.

Figure 3. Diagram of Recruitment, Enrollment, and Data Collection Procedures

Grandparent participants (GPs) indirectly recruited via their adult children by UMMHC pediatric diabetes clinicians and/or the UMASS Family Diabetes Network.

Interested GPs self-initiate phone contact with PI to learn about study / eligibility

PI asks to complete a participant declination form (Appendix H) with GPs declining participation (Aim 1)

Inclusion Criteria
- GP to grandchild with T1D aged
- 12 or less
- Hx of babysitting this grandchild
- Able to communicate in English
- Able to provide informed consent
-

Exclusion Criteria
- GP age 21 years or less
- Grandchild with T1D has co-morbidity
- GP has T1D or actively manages another's T1D
- GP participant in preliminary focus group study

Face-to-face PI/GP in-home visit
- Written fact sheet review (Appendix G)
- Verbal consent (*N* = up to 30)
- **TIME 1** Baseline data collection (Appendices A-E) for consenting GPs
- Written diabetes informational handout provided (Appendix I) to consenting GPs
- Participant number-permutation random assignment for consenting GPs (partnered GPs are assigned to same group arms)
- PI attempts to schedule the GPs CDE teaching session

HPS experimental group (*n* = up to 15)

Non-HPS control group (*n* = up to 15)

- Nurse CDE **HPS** 1:1 in-clinic teaching intervention within 2 weeks TIME 1
- Nurse CDE completes Intervention Fidelity Checklist (Appendix K)
- GPs receive written informational skills practice handout (Appendix J)
- PI conducts Intervention Fidelity Observation (*n* = total 6 HPS & non-HPS combined; randomly selected per statistician) (Appendix L)

- Nurse CDE **non-HPS** 1:1 in-clinic teaching intervention within 2 weeks TIME 1
- Nurse CDE completes Intervention Fidelity Checklist (Appendix K)
- GPs receive written informational skills practice handout (Appendix J)
- PI conducts Intervention Fidelity Observation (*n* = total 6 HPS & non-HPS combined; randomly selected per statistician) (Appendix L)

Non-responding GPs will be deemed to have passively declined continued participation after three unsuccessful attempts to contact. Additional

TIME 2 PI postal mails Repeat Measures (Appendices B-E) and Intervention Fidelity receipt checklist (Appendix M) to GPs within 1 week of CDE teaching intervention

GPs returning completed TIME 2 measures receive a hand written thank you and a $25 gift card

PI postal mails reminder postcard to non-responding GPs within 1 week TIME 2 mailing

PI places reminder phone call to non-responding GPs within 1 week of unanswered reminder postcard

- Immediately following TIME 2 data collection, purposively selected HPS and non-HPS GPs will be invited to complete **TIME 3** post-intervention qualitative phone interviews (PQI) (Appendix F) (Aim 2).

- Purposive criteria include GP highest/lowest scores on HFS-GP measure and nurse CDE assessment of most/least observed GP fear
- Interview questions, guided by self-regulation concepts, are framed to elicit GP response to receiving teaching (HPS &

GPs completing the 30 minute (estimated) TIME 3 PQI receive an additional $15 gift card

Grandparent Teaching Sessions. Two nurse CDEs, credentialed in DSMES, provide 1:1 HPS & non-HPS education sessions in a private clinic room. One CDE conducts HPS teaching sessions only, and the other CDE conducts non-HPS teaching sessions only. The content of the HPS and the non-HPS T1DM teaching sessions is identical. The difference between the experimental and the control intervention is the use of HPS to provide hands-on visual hypoglycemia management and glucagon administration teaching. Study sessions are outside of the usual nurse CDE clinic role. The two nurse CDEs are experienced in delivering the teaching sessions through their roles in PETS-D for the past 4 years. The PI will ensure CDEs are trained to deliver the adapted teaching interventions using protocol manuals detailing the basic T1DM overview and the hypoglycemia management vignette. The PI will meet with the CDEs weekly during study enrollment to discuss recruitment, retention, or intervention delivery concerns.

Experimental arm HPS intervention. Using Gaumard ® Pediatric HAL, S. 3005, child-size simulator and a glucagon practice kit, the HPS nurse CDE meets with grandparent(s) for up to 90 minutes to explain, illustrate, and review basics of T1DM and the hypoglycemia management scenario. The child simulator has a voice stream response mechanism, a bleeding finger for glucose testing, fat pads for administering injections, and simulates seizure for caregiver hands-on visual response. All capabilities are threaded throughout the hypoglycemia-teaching vignette.

Control arm non-HPS education. The non-HPS nurse CDE meets with grandparent(s) for up to 90 minutes didactic education, explaining and reviewing the same basics of T1DM and hypoglycemia management scenario, without HPS.

Intervention Fidelity: Delivery and Receipt. Following Resnick and colleagues (2005) Treatment Fidelity Framework and using the CDE Intervention Delivery Checklist (see Appendix K), PI Intervention Fidelity Checklist (see Appendix L), and Grandparent Intervention Receipt Checklist (see Appendix M), the PI will attempt to maximize study validity, and ensure that HPS & non-HPS interventions are provided as planned (Aim 1). At the conclusion of each grandparent teaching session (N = up to 30) the HPS and the non-HPS CDEs complete the CDE intervention delivery checklist to document adherence to study protocol. Early in the study, the PI will conduct one observation of nurse CDE teaching from the HPS and the non-HPS groups, using the 4-item PI intervention fidelity checklist utilizing a 4-pt likert scale (0 = no observed fidelity through 3 = higher observed fidelity; possible range 0-12). During intervention fidelity observation, the PI will monitor teaching delivery for tone, content, and intensity. An additional four sessions (randomly selected per statistician) will later be observed (n = 6) totaling 20% of all sessions, to allow opportunity to evaluate feasibility of IFP implementation & analyses. After completion of CDE teaching sessions, all grandparents (N = up to 30) complete the 18-item grandparent intervention receipt checklist exploring adequacy of content covered utilizing a 3-pt likert scale (0 = not covered through 2 = completely covered; possible range = 0- 36).

Data Management

The PI will oversee all data collection and data management. De-identified quantitative data (hard copies of measures) will be hand-collected by or mailed to the PI, then secured in a locked file cabinet within the UMASS Graduate School of Nursing (GSN) project coordinator's office. The PI will edit and check all quantitative data for completeness within 2 weeks of receipt. All entries will be visually checked by comparing the computer printouts with the original data forms. All quantitative data will be double entered. The PI will be responsible for

variable naming conventions, entering data into SPSS V. 21.0 for analysis, codebook development, and documentation of all final datasets. All final data sets will be saved to a secure UMASS mainframe storage R-drive that is automatically backed up daily. Passwords will be used to protect data files against inadvertent changes or unauthorized access.

Utilizing note-based content analysis, the PI will be responsible for managing, coding, and categorizing all qualitative data (non-recorded phone interview summaries and field notes). Documentation of data management procedures will be carefully maintained. De-identified qualitative data will be secured in a locked file cabinet in the PIs office.

Data Analysis Plan

Specific Aim #1 Data Analysis. Response rates (% interested participants enrolled) and retention rates (% participants completing) will be calculated. Demographic data from grandparents declining participation will also be analyzed and described (Aim 1). Univariate and bivariate analysis will be used to describe the sample, with descriptive statistics expressed in percentages, measures of central tendency, and standard deviations. Preliminary comparison of differences in demographics (e.g. gender, race, & ethnicity) between HPS & non-HPS groups will be explored using Chi-square & t-tests. Differences (mean within-person change) in psychosocial measure (DART, FaMM, SED, & HFS) scores between HPS & non-HPS groups will be explored. As part of Aim 1, repeated measures ANOVA will be used to examine the differences (time x group) in subscale scores for the functional family management variable, and in total scores for the functional (a) T1DM Knowledge variable; and emotional (b) Self-Efficacy and (c) Hypoglycemia Fear variables.

To assess the impact of attrition/non-response, intent-to-treat analysis will be conducted, including all randomized participants in the groups to which they were randomized. Missing data

will be extrapolated, e.g., carry forward Time 1 data to Time 2, or otherwise imputed, e.g., using regression-based imputation (Little & Rubin, 2002) for participants dropping out prior to Time 2, and results will be compared with those from a per-protocol analysis.

Intervention fidelity analysis. Preliminary comparison of differences in CDE-reported intervention delivery ($N =$ up to 30), grandparent-reported intervention receipt ($N =$ up to 30), and PI-observed intervention fidelity checklist scores ($n = 6$) between HPS & non-HPS groups will be explored using Chi-square and t-tests.

Specific Aim #2 Data Analysis. Interview data will be analyzed following the directed content analysis approach described by Hsieh & Shannon (2005). The Self-regulation framework will guide the analysis process. Initially, the PI will conduct each phone interview, summarizing it in writing. After each interview, the interviewer will record detailed field notes. Next, using the summaries, the PI begins initial coding and categorizing guided by key self-regulation concepts. The PI will review, code, and categorize all data (including field notes) and share a first draft of thematic analysis findings with the dissertation chair, an experienced qualitative researcher and T1DM family related research content expert. Later, the PI will re-review all data before finalizing qualitative data analysis. Qualitative interview questions explore grandparent learning experiences (including receptivity to HPS) and perceived participant burden. Employing quantitative and qualitative techniques will enhance illustration of the quantitative findings.

Trustworthiness. Trustworthiness will be maintained by ensuring the four essential components of credibility, confirmability, dependability, and transferability (Lincoln & Guba, 1985). Credibility (competence & accuracy) of descriptive summaries and categories is validated through prolonged engagement, persistent observation, mixed methods, and participant member checks. Confirmability and dependability are established by maintaining an audit trail of raw

data, process, and methodological notes, during data collection/analysis. Transferability is ensured by presenting richly described data for poster, presentation, and publication.

Limitations

With indirect recruitment procedures, data from grandparents declining participation may be inaccessible. With a single diverse urban setting, findings may not represent all culturally diverse populations. Although non-Hispanic Caucasian children account for a greater than expected number of children with T1DM (Dabelea, 2009; Liese et al., 2006; Lipman et al., 2013; Vehik & Dabelea, 2011) families of children with T1DM from all racial/ethnic groups attending the clinic will be actively recruited following a plan that includes community outreach, face-to-face invitation, and culturally sensitive brochures. While the efficacy of PETS-D has not yet been determined, the need for grandparents able to support their children in caring for their grandchild with T1DM has increased due to rising T1DM prevalence. No literature has yet empirically examined how grandparents learn to manage their grandchild's T1DM. This study is first to provide information on how nurses can best intervene to accomplish this task.

Human Subjects Protection

There are no anticipated physical or psychological risks to participants. There have been no published reports of physical or psychological risks for anyone using HPS to enhance the teaching-learning process. Grandparents will be informed of their right not to participate in the study. If, at any time, grandparents feel too physically or emotionally tired to continue, they have the option to end the session. There is always the potential for a loss of confidentiality when study instruments are completed. Only grouped or de-identified data will be reported in publications or presentations of findings. Data security measures will be taken to minimize risk to protect participant's personal information.

Data Security Measures

Each grandparent will be given a unique research identification number. A contact sheet containing the subject's name, address, telephone number, cell phone number, email address (if available) and the names and telephone numbers of two contact people will be completed at baseline. Because the names and numbers of people who know how to reach the participant are collected, we will find out what information can be shared with these individuals. Only the PI and the CDEs will have access to identifiable information. Personal identifiers will be stripped from all data, with the master list linking the unique research identification number and the participant's confidential contact information being stored separately in a locked file cabinet within the UMASS Graduate School of Nursing (GSN) project coordinator's office.

Conclusion

Prior to the PIs preliminary study, no previous family caregiving studies have focused specifically on grandparents who are caregivers for grandchildren having T1DM. The present proposed study explores the feasibility of educating grandparents in T1DM management using HPS, an important step toward better understanding grandparents' comprehensive T1DM management needs.

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Appendix A

Grandparent Demographic Data Form

Grandparent's current age _____

Grandparent's age when first grandchild was born_____

Grandparent Gender: M____ F_____

Grandparent's Education (number of years) _____

Ethnicity (check all that apply): American Indian/Alaskan Native_____ Black or African

American_____ Asian_____ Native Hawaiian or Other Pacific Islander_____ White_____

Race: Hispanic or Latino_____   Not Hispanic or Latino_____

Marital Status: Married___ Partnered___ Divorced/Separated___   Single___ Widowed___

Employment: Full-time___ Part-time___ Retired, no longer employed____

Residence: Urban_____   Suburban_____   Rural_____

Other than your grandchild, have you cared for anyone with T1DM? **Yes** or **No** (circle one)

Are you a practicing or retired medical professional?   **Yes** or **No** (circle one

          If yes, what type of medical professional? _____

Have you previously attended the Clara Barton T1DM Camp Caregiver Weekend? **Yes** or **No**

Gender of your adult child (the parent of your grandchild with T1DM):   M____ F_____

** Please Continue to Next Page **

These questions are specific to all of your grandchildren:

How many grandchildren in the family (total)?_____

For how many grandchildren (without T1DM) do you provide babysitting care? _____

On average, how many hrs/week are you providing babysitting care for grandchildren *without T1DM*?_____

How many of those hours include providing any type of health-related care?_____

These questions are specific to your grandchild with T1DM:

Grandchild with T1DM gender: Female____   Male____

Grandchild with T1DM age: Age in years_____   Age at diagnosis_____

Prior to your grandchild's T1DM diagnosis, on average, how many hrs/week did you babysit?_____

Since the time of your grandchild's T1DM diagnosis, on average, how many hrs/week do you babysit?____

Does your grandchild use multi-dose insulin injections? **Yes** or **No** (circle one)

Does your grandchild use an insulin pump? **Yes** or **No** (circle one)

Does your grandchild use a continuous glucose monitor? **Yes** or **No** (circle one)

Appendix B
Diabetes Awareness and Reasoning Test – Grandparent Version (D.A.R.T. – GP)
(Modified 38-item DART adapted by Sullivan-Bolyai, Bova, et al., 2012 from original 48-item
DART developed by Heidgerken et al., 2007)

1. On sick days, a person with diabetes should:
    a. sleep as much as possible
    b. not eat any carbohydrates
    c. continue to take insulin
    d. drink less water than usual

2. Hemoglobin A1C levels represent sugar levels:
    a. at that exact moment
    b. on the average over the past 3 months
    c. over the past week
    d. for the past 24 hours

3. _____ unlocks the body's cells to let in glucose:
    a. sugar
    b. carbohydrates
    c. water
    d. insulin

4. It is important for a person with diabetes to count carbohydrates in the food they eat
  because:
    a. carbohydrates have the most immediate effect on blood sugars
    b. carbohydrates are bad for people with diabetes and should be eaten in very
       small amounts
    c. insulin needs to vary according to the amount of carbohydrates eaten
    d. both a and c

5. Which of the following foods contains carbohydrates:
    a. milk products
    b. sweets such as candy, cookies, and cakes
    c. grains such as bread and pasta
    d. all of the above

6. When carbohydrate counting, a person with diabetes:
    a. does not need to worry about protein and fat in their diet
    b. should eat more fats and proteins than carbohydrates
    c. should also consider protein and fats in their diet because of their possible
       delayed effect on blood sugar
    d. both a and b

7. Which of the following contains very little or no carbohydrates:
   a. breaded, fried chicken
   b. green beans
   c. milk
   d. grilled chicken breast

8. Insulin should be injected:
   a. into the tissue or fat under the skin
   b. into a vein or artery
   c. in the arms or legs only
   d. only by a trained medical professional

9. Lantus insulin:
   a. is given immediately before each meal and snack.
   b. is a rapid-acting insulin and starts to work in 5 to 15 minutes
   c. absolutely cannot be mixed with any other insulin
   d. requires waiting 30 to 45 minutes before eating

10. A sliding scale or correction factor:
   a. is used to decide how much insulin to give based on current blood sugar
   b. calculates one's weight and how many grams of carbohydrate you need
   c. tells how many units of insulin you need per gram of carbohydrate you eat
   d. is a tiny burst of insulin given by an insulin pump.

11. Which type of insulin does **NOT** "peak"?
   a. NPH
   b. Lente
   c. Lantus
   d. Novolog

12. Air bubbles in the syringe:
   a. are not a problem
   b. can damage red blood cells if they are injected
   c. could lower the amount of injected insulin by taking up space in the syringe
   d. are caused by contaminated insulin

13. If insulin "leaks" from the injection site:
   a. the needle is being pulled out too fast.
   b. the insulin dose is too high
   c. the insulin should be injected into a lump under the skin instead
   d. it is normal & the insulin soaks back into the skin

14. An Insulin-to-Carbohydrate (Carb) Ratio:
    a. is the number of carbohydrates to be eaten each day
    b. is how many units of insulin needed per gram of carbohydrate you eat
    c. is only important if you use Ultralente
    d. is used to decide how much insulin you should give based on your current blood sugar

15. If a person with diabetes is taking Lantus:
    a. they also need to give rapid-acting insulin with meals or snacks
    b. they only need to give insulin 1 time each day
    c. they don't need to check their blood sugar as often
    d. they will need to eat breakfast to cover the Lantus "peak"

16. How does insulin work?
    a. insulin raises blood sugar by preventing glucose from entering the cell membranes
    b. insulin lowers blood sugar by moving glucose from the blood into the cells of your body.
    c. insulin stimulates the islet cells in the pancreas to produce metabolic enzymes
    d. insulin decreases the amount of glucose made by the brain

17. Glucagon is:
    a. given if the blood sugar is less than 80
    b. mixed with NPH and given 30 minutes before eating a meal or snack
    c. are tablets for treating hypoglycemia that contain 15 grams of fast-acting carbohydrates
    d. an emergency injection for a person with diabetes who is unconscious from low blood sugar.

18. In people with Type 1 Diabetes:
    a. the pancreas no longer makes insulin
    b. produce some insulin but have problems with insulin absorption
    c. insulin can be taken as a pill
    d. as many as 40% of people are unaware of their disease

19. If moderate or large ketones are present, which of the following is **NOT** true?
    a. rapid or fast-acting insulin can be given
    b. the individual should take 3 glucose tablets and recheck in fifteen minutes
    c. urine should be tested again in 2-3 hours
    d. the person should drink more fluids

20. What is Diabetic Ketoacidosis (DKA)?
        a. a condition when the blood sugar gets too low.
        b. when the body has to break-down fat for energy
        c. a problem caused by drinking too much water
        d. all of the above

21. Why should a person with diabetes "push-fluids" when they are sick?
        a. to prevent dehydration and push ketones out of their body
        b. to keep awake by "pushing" on their bladder
        c. to prevent hypoglycemia
        d. all of the above

22. Which of the following statements is true?
        a. for negative/trace ketones, give extra insulin
        b. for negative/trace ketones, give no extra insulin
        c. for moderate or large ketones, give no extra insulin
        d. for moderate or large ketones, eat 30 grams of carbohydrates immediately

23. If your grandchild/teen has moderate/large ketones, they should:
        a. eat 30 grams of carbohydrates
        b. take extra fast-acting insulin as directed by the doctor
        c. take extra long-acting insulin as directed by the doctor
        d. all of the above

24. How often should your grandchild/teen with diabetes check for ketones when they're sick?
        a. every 4-6 hours, even if the blood sugar is not high.
        b. if their blood sugar is > 240mg/dL
        c. if they are vomiting
        d. all of the above

25. All of the following increase the likelihood of damage to the eyes, except:
        a. smoking
        b. poor school grades
        c. high blood pressure
        d. poor diabetes control as a teenager

26. A student may need to leave school if:
        a . moderate to large ketones and vomiting are present
        b. they have low blood sugar
        c. insulin is needed
        d. glucophage is needed

27. If a child has a blood glucose level of 240mg/dL, then:
      a. the child should be given insulin and sent immediately to class
      b. the child should be given insulin and sent to class after approximately 30 minutes
      c. the parent should be called, the child needs to go home
      d. the child should check for ketones in their urine and follow the written treatment plan for that child

28. A student with diabetes is permitted to eat lunch or a snack:
      a. during regularly scheduled lunch and snack times
      b. at times designated by their Health Care Plan
      c. whenever needed to treat a low blood sugar
      d. all of the above

29. A meal with a sandwich (i.e., 2 pieces of bread with lean turkey and lettuce) and a diet soda has:
      a. 700 grams of carbohydrates
      b. 30 grams of carbohydrates
      c. 2 grams of carbohydrates
      d. 0 grams of carbohydrates

30. Your grandchild's target blood sugar range is 70 to 150. Your grandchild's current blood sugar is 65, you should:
      a. treat with 15 grams of fast-acting carbohydrates
      b. go ahead and eat your next meal early
      c. do nothing
      d. wait and check blood sugar in 30 minutes to see if blood glucose level is higher

31. Symptoms of a blood glucose level less than 40 mg/dL can include:
      a. appearing dazed and confused
      b. seizures
      c. appearing drunk
      d. all of the above

32. If there are swollen or lumpy areas in any of the injection sites, you should:
      a. find an area near the swollen site to use
      b. put warm compresses on the swollen site
      c. not use that site because the insulin may be absorbed at a different rate causing irregular blood sugars
      d. use the site with a longer needle

33. Which of these steps is important to remember when drawing up insulin:
      a. Wash your hands before giving the injections
      b. Be very precise about the dosage
      c. Immediately vent the insulin bottle
      d. Both A and B

34. You grandchild has a glucose blood level of 58, is alert, but irritable. You would:
      a. give a small (6 ounces) glass of milk or juice, wait 10 minutes, and recheck blood glucose.
      b. call the doctor
      c. the child has done this before, watch him and retest in 15 minutes
      d. try to distract him with a game or television

35. It is **especially** important to test in the middle of the night:
      a. with sleepovers with friends and extra activity
      b. when your grandchild had a quiet day without much activity
      c. when someone new is watching the child
      d. all of the above

36. Common problems causing inaccurate blood sugar test results can include:
      a. testing finger is not clean and dry
      b. strips are expired
      c. strips have been exposed to heat or frozen
      d. all of the above

37. One of the principles of food management is to follow a well-balanced meal plan. This plan includes limiting fat consumption to:
      a. 45-65% of daily intake
      b. 20-35% of daily intake
      c. 10-15% of daily intake
      d. One high fat food item per day

38. Exercise is important in diabetes management because it:
      a. lowers blood sugar levels
      b. helps keep blood fat levels (HDL) normal
      c. improves insulin response
      d. all of the above

Appendix C
Family Management Measure - Grandparent (FaMM)
(Knafl et al., 2009)

INSTRUCTIONS:

This questionnaire is about how your family manages caring for a grandchild with T1DM. 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. Many of these questions use the word "family". This refers to those people that you and your grandchild think of as family.

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

	Strongly Disagree				Strongly Agree
	1	**2**	**3**	**4**	**5**
1. Our grandchild's everyday life is similar to that of other children his/her age.					
2. Our grandchild's diabetes gets in the way of family relationships.					
3. Our grandchild's diabetes requires frequent visits to the clinic.					

	Strongly Disagree				Strongly Agree
	1	**2**	**3**	**4**	**5**
4. In the future we expect our grandchild to take care of his/her diabetes.					
5. Our grandchild enjoys life less because of diabetes.					
6. Taking care of our grandchild's diabetes is often overwhelming.					
7. Our grandchild's diabetes is like a roller coaster with lots of ups and downs.					
8. Our grandchild's diabetes is the most important thing in our family.					
9. It is very hard for us to take care of our grandchild's diabetes.					

	Strongly Disagree 1	2	3	4	Strongly Agree 5
10. Our grandchild takes part in activities he/she wishes to despite his/her diabetes.					
11. Because of diabetes, we worry about our grandchild's future.					
12. Our grandchild's diabetes doesn't take a great deal of time to manage.					
13. We have some definite ideas about how to help our grandchild live with his/her diabetes.					
14. Despite his/her diabetes, we expect our grandchild to live away from home in the future.					
15. We have enough money to manage our grandchild's diabetes.					

	Strongly Disagree 1	2	3	4	Strongly Agree 5
16. Our grandchild is different from other children his/her age because of his/her diabetes.					
17. It is difficult to know when our grandchild's diabetes must come first in the family.					
18. We are looking forward to a happy future with our grandchild.					
19. When something unexpected happens with our grandchild's diabetes, we usually know how to handle it.					
20. Our grandchild's friendships are different because of his/her diabetes.					

	Strongly Disagree 1	2	3	4	Strongly Agree 5
21. We expect to be devoting less time to our grandchild's diabetes in the future.					
22. Diabetes makes family life very difficult.					
23. Our grandchild's diabetes rarely interferes with other family activities.					
24. Our grandchild's diabetes requires frequent hospital stays.					
25. We feel we are doing a good job taking care of our granchild's diabetes.					
26. People with diabetes have a normal length of life.					
27. It's more difficult to know if we need to be more protective of our grandchild.					

	Strongly Disagree 1	2	3	4	Strongly Agree 5
28. We often feel unsure about what to do to take care of our grandchild's diabetes.					
29. Our grandchild's diabetes will be harder to take care of in the future.					
30. We think about our grandchild's diabetes all the time.					
31. It seems as if our grandchild's diabetes controls our family life.					
32. Many other conditions are more serious than our grandchild's.					
33. It is hard to get anyone else to help us with our grandchild's diabetes.					

	Strongly Disagree 1	2	3	4	Strongly Agree 5
34. We have not been able to develop a routine for taking care of our grandchild's diabetes.					
35. It takes a lot of organization to manage our grandchild's diabetes.					
36. We are sometimes undecided about how to balance the diabetes and family life.					
37. It is hard to know what to expect of our grandchild's diabetes in the future.					
38. Even though our grandchild has diabetes, we have a normal family life.					
39. Our grandchild would do better in school if he/she didn't have diabetes.					

	Strongly Disagree 1	2	3	4	Strongly Agree 5
40. We are confident that we can take care of our grandchild's diabetes.					
41. We have goals in mind to help us manage our grandchild's diabetes.					
42. It is difficult to fit care of our grandchild's diabetes into our usual family routine.					
43. Dealing with our grandchild's diabetes makes family life more difficult.					
44. We know when our grandchild needs to be a child.					
45. Diabetes makes it hard to live a normal life.					

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. If you currently have a partner, please proceed to the next page. If you currently 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 grandchild's diabetes.					
47. My partner and I have different ideas about how serious our grandchild's diabetes is.					
48. I am pleased with how my partner and I work together to manage our grandchild's diabetes.					
49. My partner and I argue about how to manage our grandchild's diabetes.					

	Strongly Disagree				Strongly Agree
	1	**2**	**3**	**4**	**5**
50. My partner and I consult with each other before we make a decision about our grandchild's care.					
51. My partner and I have similar ideas about how we should be raising our grandchild.					
52. I am unhappy about the way my partner and I share the management of our grandchild's diabetes.					
53. My partner and I support each other in taking care of our grandchild's diabetes.					

Appendix D

Self-Efficacy, Diabetes – Grandparent (SED –GP)

(Grossman et al., 1987)

Instructions: Please read the following items. After each statement, circle the number from 1 to 5 that shows how much you believe you can or cannot do what is asked *now*.

	Very sure I can't	Sure I can't	Maybe I can	Sure I Can	Very sure I can
1. Be the one in charge of drawing up and giving the insulin injection / insulin bolus to my grandchild.	1	2	3	4	5
2. Checking and keeping track of my grandchild's blood glucose levels.	1	2	3	4	5
3. Checking my grandchild's urine for ketones.	1	2	3	4	5
4. Recognize and treat a high blood sugar, with or without ketones.	1	2	3	4	5
5. Prevent my grandchild from having low blood glucose levels.	1	2	3	4	5
6. Keep my grandchild free from having high blood glucose levels.	1	2	3	4	5

	Very sure I can't	**Sure I can't**	**Maybe I can**	**Sure I Can**	**Very sure I can**
7. Avoid hypertrophy, or lumps, at injection / pump sites.	1	2	3	4	5
8. Recognize patterns of blood glucose levels that indicate a need for insulin dose / basal rate adjustment.	1	2	3	4	5
9. Contact the diabetes team for help	1	2	3	4	5
10. Care for my grandchild when he or she is sick or cannot eat.	1	2	3	4	5
11. Follow a consistent schedule for diabetes management (eating meals, snacks, giving insulin).	1	2	3	4	5
12. Prevent long term complications from my grandchild's diabetes.	1	2	3	4	5
13. Have some control over my grandchild's diabetes.	1	2	3	4	5
14. Follow the team's recommendations for taking care of my grandchild's diabetes.	1	2	3	4	5

	Very sure I can't	Sure I can't	Maybe I can	Sure I Can	Very sure I can
15. Instruct school personnel / coaches about my grandchild's diabetes care.	1	2	3	4	5
16. Talk with people I know in the community about my grandchild's diabetes.	1	2	3	4	5
17. Talk with other family members / my other grandchildren about diabetes.	1	2	3	4	5
18. Talk with my grandchild about his / her diabetes.	1	2	3	4	5
19. Run my life similarly to before my grandchild was diagnosed with diabetes.	1	2	3	4	5
20. Go on vacation, with or without my grandchild with diabetes.	1	2	3	4	5
21. Leave my grandchild with someone else / use a babysitter.	1	2	3	4	5

	Very sure I can't	Sure I can't	Maybe I can	Sure I Can	Very sure I can
22. Find out more information about diabetes.	1	2	3	4	5

For items that you responded 1 or 2, please tell us a little about **why** you believe you can't:

_____

_____

_____

_____

_____

_____

_____

_____

Appendix E

Hypoglycemia Fear Survey - Grandparents of young children (HFS-GP)

(Clarke et al., 1998)

Instructions: Below is a list of concerns that grandparents of grandchildren with diabetes sometimes have. Please read or listen to each item carefully and select the number that best describes how often you WORRY about each item because of your grandchild's low blood sugar.

I WORRY ABOUT....

		Never	Rarely	Some-times	Often	Always
1	Not recognizing that my grandchild is having a hypoglycemic event	0	1	2	3	4
2	Not having food or fruit juice with me for my grandchild	0	1	2	3	4
3	Having my grandchild dizzy or passing out in public	0	1	2	3	4
4	Feeling that my grandchild will have a low blood sugar while he/she is asleep	0	1	2	3	4
5	My grandchild embarrassing him/herself in front of friends/family in a social situation	0	1	2	3	4

		Never	**Rarely**	**Some-times**	**Often**	**Always**
6	My grandchild having a low blood sugar when he/she is away from me	**0**	**1**	**2**	**3**	**4**
7	My grandchild being disoriented	**0**	**1**	**2**	**3**	**4**
8	My grandchild losing control	**0**	**1**	**2**	**3**	**4**
9	No one being around to help my grandchild during a hypoglycemic event	**0**	**1**	**2**	**3**	**4**
10	My grandchild making a mistake or having an accident at daycare/school	**0**	**1**	**2**	**3**	**4**
11	My grandchild getting a bad evaluation at daycare/school because of something that happens when his/her sugar is low	**0**	**1**	**2**	**3**	**4**
12	My grandchild having seizures	**0**	**1**	**2**	**3**	**4**
13	My grandchild developing long-term complications from frequent low blood sugars	**0**	**1**	**2**	**3**	**4**
14	My grandchild feeling light headed or faint	**0**	**1**	**2**	**3**	**4**

		Never	Rarely	Some-times	Often	Always
15	My grandchild having an insulin reaction	0	1	2	3	4
16	My grandchild having a hypoglycemic event while I'm driving	0	1	2	3	4

Below is a list of things people with diabetes sometimes do in order to avoid low blood sugar. Read or listen to each item carefully. Select the number that best describes what you do during your daily routine to AVOID low blood sugar in your grandchild.

I TRY TO...

		Never	Rarely	Some-times	Often	Always
17	Feed my grandchild large snacks at bedtime	0	1	2	3	4
18	Avoid allowing my grandchild to be away from me when his/her sugar is likely to be low	0	1	2	3	4
19	Try to run a little high to be on the safe side	0	1	2	3	4
20	Keep my grandchild's sugar higher when he/she will be away from me	0	1	2	3	4

		Never	Rarely	Some-times	Often	Always
21	Feed my grandchild as soon as I feel or see the first signs of low blood sugar	0	1	2	3	4
22	Reduce my grandchild's insulin when I think his/her blood sugar is low	0	1	2	3	4
23	Keep my grandchild's blood sugar higher when I know he/she is planning to be at a long event (e.g. school, party)	0	1	2	3	4
24	Always carry fast-acting sugar	0	1	2	3	4
25	Don't allow my grandchild to play excessively when I think his/her blood sugar is low	0	1	2	3	4
26	Check my grandchild's blood sugar often when he/she is planning to be at a long event (e.g. school, party)	0	1	2	3	4
27	Check my grandchild's blood glucose levels while he/she is asleep because I don't want it to go low	0	1	2	3	4

Appendix F

Semi-structured Qualitative Interview Guide

Questions	Probes
Tell me about the written material you were given to review before your teaching session.	What was helpful? What wasn't helpful?
Tell me what the teaching experience was like for you compared to other teaching sessions you may have had.	What was helpful? What wasn't helpful?
What was your initial reaction to the teaching session?	Was the concept / idea scary?

	How could we make it less scary?
Tell me about the hypoglycemia-teaching scenario.	Amount of Practice Time Realistic? Cueing used by the diabetes nurse? What would you recommend?
Tell me about the skill practice.	Glucose Checks Drawing up and administering glucagon Did the practice help you feel more competent with the skills?

Overall, is this type of teaching something you think should be offered to other grandparents having grandchildren with T1DM?	
Since the time of your teaching session, on average, how many hrs/week do you babysit your grandchild with T1DM?	
Tell me about the forms that you were asked to complete.	
What I did: What I noticed: What I felt:	

Appendix G

Written Study Fact Sheet

Insert Docket #_____   **Insert Fact Sheet Version # or Date**_____

UNIVERSITY OF MASSACHUSETTS MEDICAL SCHOOL

COMMITTEE FOR THE PROTECTION OF HUMAN SUBJECTS IN RESEARCH

A. You are invited to participate in a research study called *Grandparent Education through Simulation – Diabetes (GPETS-D)*

B. The purpose of this study is to explore using simulation to teach T1DM management information and skills to grandparents of grandchildren with T1DM

C. You will be enrolled for *approximately 8 weeks.* This will require *an initial meeting at your home (or a place convenient for you), one* visit to the clinic, one postal mailing of forms to complete, *and one phone call for select participants.*

D. As part of this study, you will be required to attend one educational session with a certified diabetes educator. You will also complete two sets of written questionnaires (5 forms). Select participants (up to 30) will be asked to complete a telephone interview at the end of the study.

E. The only risk of being in this study is that your personal information could be lost or exposed. This is very unlikely to happen, and we will do everything to make sure that your information is protected.

F. Participation is voluntary. You do not have to be in this study, and if you do participate, you are free to leave at any time. In either case, there are no penalties and you do not lose any benefits to which you are otherwise entitled. The care you or your grandchild receives at UMass Memorial Health Care will not be affected if you decide to not be in the study or to quit after joining.

G. We will try to limit access to your personal information to people who have a need to review this information. We cannot promise complete privacy. The UMMS Institutional Review Board and other representatives of UMMS may see your information.

H. If you have any questions, concerns, or complaints, or think that the research has hurt you, you can talk to the research team at University of Massachusetts, Worcester, Graduate School of Nursing, 1-508-856-5801 or LauraLynn.Maguire@umassmed.edu. This research has been reviewed and approved by an Institutional Review Board. You can reach them at (508) 856-4261 or irb@umassmed.edu if you would prefer to speak with someone not associated with the study or have questions about your rights as a research subject.

Appendix H

Participant Declination Form*

* Please **Do Not Use** this form if the patient does not fall within the study age range

Grandparent current age _____

Grandparent's age when first grandchild was born_____

Parent Gender: M____   F_____

Grandparent's Education (number of years) _____

Ethnicity (check all that apply): American Indian/Alaskan Native_____   Black or African

American_____   Asian_____   Native Hawaiian or Other Pacific Islander_____   White_____

Race: Hispanic or Latino_____   Not Hispanic or Latino_____

Marital Status: Married___ Partnered___ Divorced/Separated___ Single___ Widowed___

Employment: Full-time___ Part-time___ Retired, no longer employed____

Residence: Urban_____   Suburban_____   Rural_____

Age of Grandchild with T1DM _____

Reason (s) for Opting Out of this study

Too stressful_____   Too busy_____   Not interested _____

Ineligible _____

Reason for ineligibility:_____

Other:_____

_____

_____

Appendix I

Written Informational T1DM Handout

Type 1 Diabetes Mellitus (T1DM)

Learning that your grandchild has been diagnosed with T1DM can be a very emotional and stressful time for grandparents. The grandparent T1DM education study team is made up of a team of health care professionals working together with you, to help you gain knowledge to support your grandchild and their parents with managing their T1DM.

What is T1DM?

T1DM is a disease in which blood glucose levels are above normal. Most of the food we eat is turned into glucose, or sugar, for our bodies to use for energy. The pancreas, an organ that lies near the stomach, makes a hormone called insulin to help glucose get into the cells of our bodies. When you have diabetes, your body either doesn't make enough insulin or can't use its own insulin as well as it should. This causes sugar to build up in your blood.

T1DM has a relatively sudden onset and generally is diagnosed before age 20. With T1DM, your pancreas stops making insulin because the body's immune system has destroyed the cells that make insulin. Insulin injections are needed for your entire life. Oral (by mouth) medications alone cannot control T1DM. Insulin is always needed for T1DM.

The exact cause of T1DM is not known. Genetic (inherited) factors may contribute to the development of T1DM. T1DM is not caused by eating too many sweets and it is not contagious.

It is important to have good blood sugar control to minimize both the short-term and long-term complications associated with T1DM. *Short-term complications* from high (hyperglycemia) and low (hypoglycemia) blood sugars can cause your grandchild to not feel well, lead to time away from school or other activities or hospitalization. *Long-term complications* can occur when blood sugar level have been high for long periods of time (years). Complications may include damage to the eyes, kidneys, nerves, and blood vessels. The Diabetes Control and Complication Trial, an important study published in 1993, reported that people who kept their blood sugar values closest to the non-diabetic range had less damage to these important organs.

Important Points

- T1DM is a condition in which there is a lack of insulin in the body

- There was nothing you could have done to prevent you grandchild's T1DM.

- There are three major factors which must be balanced to maintain healthy blood sugar control: food, activity levels, and insulin

- Food increases blood sugar levels, and activity and insulin lower blood sugar levels.

Insulin

Insulin is a hormone made by the pancreas. The pancreas is an organ located in the abdomen behind the stomach. Specific cells in your pancreas called **beta cells** produce insulin.

Insulin is needed to help the sugar in blood move into cells, where it is burned for energy. The sugar in our blood comes from foods (carbohydrates) that we eat; these sugars are stored and released by the liver. However, if you have **T1DM** the beta cells have been destroyed by an autoimmune process, therefore you stop making insulin. When the body does not produce its own insulin (endogenous insulin), insulin needs to be replaced from outside the body (exogenous insulin). This can only be done by injecting insulin into the body. Insulin is a protein; therefore, if it were given by mouth the normal digestive system would destroy it.

Insulin is divided into three groups:

- Rapid/Short acting (Humalog, Novolog, Apidra, Regular)
- Intermediate acting (NPH)
- Long acting (Lantus, Levemir)

The action of each insulin group once it has been injected			
Type of Insulin	**Starts to work**	**Works it hardest**	**How long it lasts**
Rapid/Short-acting			
Humalog, Novolog, Apidra	10 to 15 minutes	30 to 90 minutes	3 to 4 hours
Regular	30 to 60 minutes	2 to 4 hours	4 to 6 hours
Intermediate-acting			
NPH	1 to 2 hours	4 to 10 hours	10 to 15 hours
Long-acting			
Lantus, Levemir	1 to 2 hours	2 to 22 hours	24 hours

The diabetes nurse educator will discuss with you type of insulin your grandchild is taking and how often they are taking it. Understanding how your child's insulin works helps you to assess your grandchild's response to their diabetes management regimen.

Your diabetes nurse educator will help draw the action of your child's insulin regimen for a day. This is important to know because your child's insulin and food need to work together.

7am   10am 12pm 3pm   6pm   9pm   12am 3am   7am

Breakfast   Lunch   Dinner Bed

Important Points:

- The diabetes nurse educator will review with you a daily schedule of blood sugar checks, insulin doses, and meal and snack times.

- Staying on this schedule (within one hour) each day is recommended.

- Is it dangerous for your grandchild to miss an insulin dose? Potentially, if a dose is missed, check your grandchild's blood sugar and ketone levels. Call the diabetes team to receive instructions for how much missed insulin to give and if other adjustments need to be made for the remainder of that day.

Storage of Insulin

- Unopened insulin should be stored in the refrigerator in the original box. It will last until the expiration date stamped on the box. The expiration dates is also stamped on the vial or pen it.

- The insulin currently in use (opened) should be kept at room temperature (>32◦ and <86◦). This **insulin MUST be discarded 28 days after it has been opened**. Keeping it in the refrigerator does not make this insulin last longer once it has been opened. (These guidelines are different for some insulin pens, please check the package insert)

- Insulin stored at room temperature, whether or not it is opened, is only good for 28 days, regardless of the expiration date.

Low Blood Sugar (Hypoglycemia)

Low blood sugar is any blood sugar level that is below 70 mg/dl. Medications to treat diabetes (such as insulin) can lead to low blood sugars. Low blood sugar reactions usually occur quickly so recognizing the symptoms and treating a low blood sugar is important to prevent a more severe reaction.

Low Blood Sugar (Hypoglycemia) Symptoms

Symptoms of low blood sugar often start as **mild** and become **severe** if not treated. Symptoms of low blood sugar may include:

Mild: Hunger   Irritability

                 Weakness   Paleness

                 Shakiness   Tiredness

                 Headache   Difficulty concentrating

Severe: Drowsiness

                 Behavior changes

                 Loss of consciousness

                 Seizure

Low Blood Sugar (Hypoglycemia) Causes

Causes of low blood sugars include:

- Too much insulin – more insulin than you need to balance with your food and activity, the dose you are on is currently too high or you gave more than prescribed

- Increased exercise or activity

- Not enough food for the insulin you took

- Giving an insulin injection into the muscle and not the fat

Low Blood Sugar (Hypoglycemia) Treatment

The Rule of 15's. Treatment for low blood should not be delayed. Carry a fast acting carbohydrate with you at all times. If low blood sugar is suspected, do a blood sugar check immediately.

For a MILD to MODERATE low blood sugar reaction:

Have your grandchild eat or drink **15 grams** of fast acting carbohydrate. Examples are: 4 oz juice, 3 or 4 glucose tablets, 8 oz of low fat milk, 6 oz regular soda, 4 tsp white table sugar, 1 small tube of cake icing/gel.

Wait 10 to 15 minutes and recheck your blood sugar level:

1) If your grandchild's blood sugar is **under 70** - treat with another **15 grams** of fast-acting carbohydrate.

2) If your grandchild's blood sugar is **over 70** – if your grandchild is going to have a meal or snack within the next hour no additional snack is needed. However, if your grandchild will not be eating a meal or snack within the next hour then they should have a snack containing **15 grams** of complex carbohydrate.

For a SEVERE low blood sugar reaction:

A **glucagon injection** should be given if your grandchild is unconscious, having a seizure or semi-conscious (unable to safely take something by mouth due to choking risk). One of the Diabetes Educators will show you how to mix and give a glucagon injection.

Glucagon is a hormone made by our body that has the opposite effect as insulin and raises our blood sugar. Glucagon is a powder that must be dissolved prior to injecting it. Glucagon can be stored at room temperature, (above 32 degrees and below 90 degrees). A side effect of Glucagon is nausea and vomiting. Therefore, it is important to have an unconscious child lying on his/her side to avoid choking. If the blood sugar is not improving within 15 to 20 minutes then a second dose of glucagon can be given. Once awake the child should be given fast-acting carbohydrate (juice, regular soda) followed by a snack of complex carbohydrate and protein (crackers and cheese). If your grandchild has a severe low blood sugar reaction, the diabetes team should be notified.

Important Points

- Low blood sugar reactions can happen fast, always carry a fast-acting carbohydrate with you

- Use the "Rule of 15's" to treat low blood sugars

- A Glucagon injection is the treatment for a severe low blood sugar

High Blood Sugar (Hyperglycemia)With and Without Ketones

For your grandchild a high blood sugar is one that is above their target range. It is expected that your grandchild will have some blood sugars above or below their target range, but remember it is our goal that at least 75% of their blood sugars will be within their target range.

High Blood Sugar (Hyperglycemia) Symptoms

Symptoms of high blood sugar may include:

- Increased thirst and urination
- Waking at night to void or bed wetting
- Hunger
- Flushed face
- Yeast infections.

High Blood Sugar (Hyperglycemia) Causes

Causes of High blood sugars include:

- Not enough insulin
- Too much food containing carbohydrates
- Decreased activity or exercise
- Illness or stress.

Potential Consequence of High Blood Sugar (Diabetic Ketoacidosis)

Ketones are a by-product of the breakdown of fat. The body produces ketones to provide energy when there is not enough insulin in the system to use sugar as fuel. The build up of ketones can lead to a condition called **acidosis**, which is life threatening. **Diabetic ketoacidosis** is preventable in people who know they have diabetes. Ketones can be tested in both blood and urine. One of the diabetes nurse educators will show you how to check ketones.

Monitoring Ketones

If your grandchild receives their insulin by injection (not from a pump), you must check for ketones every time:

- Your grandchild is ill
- Your grandchild's blood sugar is over 300 before breakfast or at bedtime
- Your grandchild's blood sugar is over 300 for two consecutive blood sugar checks
- Your grandchild misses a dose of insulin

High Blood Sugar (Hyperglycemia) Treatment

High Blood Sugar Treatment WITHOUT Ketones:

When you get a high blood sugar level, you want to think back over the last few hours to see if you can determine why it may be high. This could be because:

- Extra carbohydrate was eaten at the last meal or snack

- Carbohydrate was eaten too close to the blood sugar check

- Not enough insulin, the dose may need to be increased if this is a pattern, insulin may have leaked out at the last injection, or a dose was forgotten or missed

- Less than usual exercise or activity

- Illness

Your grandchild's insulin regimen is designed to correct high blood sugar reading (checked pre-meal) by increasing your grandchild's insulin dose when blood sugars are high. It is important to determine a possible cause of high blood sugar in order to prevent it from happening again. However, there will be times your grandchild has both high and low bloods sugars with no obvious cause.

<u>High Blood Sugar Treatment WITH Ketones</u>

Remember ketones tell us that your grandchild's body is burning fat for energy not sugar. This most often occurs because there is not enough insulin in the body. Early detection and correction of **ketones** is critical as the build up of ketones can lead to diabetic ketoacidosis (DKA) which can be life threatening.

Extra insulin may be needed to correct ketones. The amount of extra insulin is calculated based on the total daily dose of insulin your grandchild takes and the level of ketones. These additional doses of insulin may be given every two to three hours. Addition fluids are also recommended.

Blood sugar and ketone levels will need to be checked every 2 hours until the ketones are no longer present.

Important Points

- Your grandchild may have some high or low blood sugar results, but a pattern of any blood sugars means something needs to be adjusted

- Ketones are checked when:
  - ✓ Your grandchild is ill or there is a stress on the body
  - ✓ Blood sugar is over 300 pre-breakfast or at bedtime
  - ✓ Blood sugar is over 300 two consecutive blood sugar checks
  - ✓ Insulin has been missed

- Diabetic ketoacidosis is preventable for those who know they have diabetes

Appendix J

Written Informational Skills Practice Handout

Drawing up Insulin and Insulin Injections

Supplies you will need:

Insulin

Syringe

Alcohol wipe

Scale or formula to determine the dose

Drawing up Insulin:

- Remove cap from bottle, date it or if opened check date

- Wipe tops of bottle with alcohol
- Draw air into the syringe equal to the volume of insulin to be given
- With vial upright, inject the air into the bottle of insulin
- Invert the bottle to withdraw the insulin. To clear air bubbles: pull the plunger to between 5 and 10 on the syringe and slowly push all the insulin back into the bottle. Then withdraw the correct dose. If bubbles are still present, repeat this step.
-

Giving an Insulin Injection:

- Identify appropriate sites for injecting insulin (if site appears puffy, hard, swollen or dimpled use another site)
- Clean site with alcohol and let dry
- Lift up the skin with a gentle pinch
- Insert needle the total length at a 90 degree angle
- Push the plunger down all the way (to the needle hub)
- Wait 5 to 10 seconds then release the pinch and remove the needle. This will help to prevent leak back (when a drop of insulin comes back out)

Important Points

- Rotate injection site to avoid hypertrophy (changes in the tissue that will affect how the insulin works).

- Lantus cannot be mixed with other insulins. It is recommended that one site of the body be used only for Lantus, often the buttocks.

Blood Glucose Monitoring

Remember, when someone does not have diabetes their blood sugar is between 70 and 120. Your grandchild's diabetes nurse educator will discuss with you the range your grandchild's blood sugar levels should be. It is often not possible to keep blood sugars in the non-diabetic range. Our goal is to keep your grandchild's blood sugar levels in their target range 75% of the time. Part of your new daily routine will now include checking your grandchild's blood sugar levels. This is done routinely four times a day, before breakfast, before lunch, before dinner and before the bedtime snack. A droplet of blood is obtained by pricking the finger. Next, the blood is applied to a special test strip that is inserted into the blood glucose monitor (or meter) that your grandchild uses at home (and school). A diabetes nurse educator will show you how to use the meter.

It is important that you record all your grandchild's blood glucose readings. Your grandchild has a logbook to write them in. Many blood glucose meters also have a memory feature allowing blood glucose readings to be uploaded to a computer. **Whatever method you use, it is important to review your grandchild's blood sugar patterns on a regular basis.** If the pattern of your child's blood sugar numbers is higher or lower than their target range then a change or adjustment may be needed in their diabetes plan.

It is important to keep your grandchild's blood sugar levels in their target range to help them feel well and energetic. However, it is also important to prevent other health issues that can develop after years of poorly controlled blood sugar levels. The Hemoglobin Alc (HgbAlc) is a blood test that your grandchild will have about every three months. The HgbA1c test indicates an average blood sugar number for the last three months. Your grandchild's diabetes team will recommend an expected HgbAlc goal for your grandchild.

Important Points

- Blood sugar levels are checked four times a day, before breakfast, before lunch, before dinner and before bedtime snack (even if you are not eating a meal).

- Blood sugar records need to be checked regularly to see if changes need to be made in your grandchild's diabetes plan

Blood Sugar Level Goals

Based on ADA recommendations your grandchild's blood sugar goal is:

Age	Blood Sugar Before Meals	/ Bedtime/Overnight
Below six years	100 – 180	110 – 200
6 – 12 years	90 – 180	100 – 180
13 – 19	90 – 130	90 – 150
>19 years	90 – 130	

Care and Storage of Supplies and Equipment

Insulin

Once you have removed the plastic cap from the top of the insulin bottle, it can be stored at room temperature for one month without losing its potency. Labels on bottles of insulin state "keep in a cool place, avoid freezing". This does not mean refrigeration is necessary. A cool, dry place away from sunlight would be ideal to store your **opened** bottles. You should keep extra bottles (those that have not been opened) of insulin on the door of your refrigerator (not the freezer), until you are ready to use them. Once opened, leave them at room temperature, (less than 86 degrees). The expiration date on a bottle of insulin indicates potency until that date for unopened, refrigerated insulin.

Syringes and Lancets

Disposable syringes were designed to be used once and discarded. Collect used syringes in a container that can be easily secured, e.g. liquid laundry detergent bottle. When the container is full, secure the top with tape. Please check with your local ordinances and trash hauler for any special disposal guidelines for "home medical waste".

Blood and Urine Test Strips

Keep your blood and urine strips in their original containers with the tops on. Moisture can affect these strips, so keep them in a cool dry place. Use the strips within the recommended time period. Blood glucose test strips can be checked for accuracy by using the appropriate "control" solution. Urine ketone strips may be checked by dipping in nail polish remover containing acetone. Ketone strips are good for four months once the bottle has been opened.

Appendix K

Certified Diabetes Educator (CDE) Intervention Delivery Checklist

At the conclusion of each teaching session, HPS and non-HPS CDEs will complete a treatment delivery checklist documenting content covered.

Nurse CDEs name running session:

Simulation session time (in minutes):

Information Covered:

Basic T1DM Overview   YES / NO (circle one)

Review of written T1DM handout   YES / NO (circle one)

Hypoglycemia daytime   YES / NO (circle one)
Caregiver response:

Hypoglycemia nighttime   YES / NO (circle one)
Caregiver response:

Tremor observation and practice YES / NO (circle one)
Caregiver response

Technical Skill Practice   YES / NO (circle one)

Glucose checks with monitor   YES / NO (circle one)
Caregiver response:

Mixing glucagon   YES / NO (circle one)
Caregiver response:

Administering glucagon   YES / NO (circle one)
Caregiver response:

CDE Assessment of Observed T1DM Management Fear: 0   1   2   3   4

                                                  Less   More

                         Fearful ←----------------------→ Fearful

Appendix L

Primary Investigator (PI) Intervention Fidelity Observation Checklist

CDE Initials:_____

Observer Initials:_____

Circle Group: Intervention (HPS) **OR** Control (non-HPS)

Response Options:

   0 = none
   1 = low level of intervention fidelity
   2 = moderate level of intervention fidelity
   3 = high level of intervention fidelity

<u>Intervention (HPS) Group Questions</u>

1. Information covered is consistent with the HPS manual/written scenario:_____

2. Skills covered are consistent with the HPS manual/written scenarios:_____

3. Responsiveness to caregiver questions is consistent with HPS standard of care:_____

4. Evidence of positive interactions between grandparents and educators:_____

                                        TOTAL SCORE:_____

<u>Control (non-HPS) Group Questions</u>

1. Information covered is consistent with the non-HPS manual/written scenario:_____

2. Skills covered are consistent with the non-HPS manual/written scenarios:_____

3. Responsiveness to caregiver questions is consistent with non-HPS standard of care:_____

4. Evidence of positive interactions between grandparents and educators:_____

                                        TOTAL SCORE:_____

Appendix M

Grandparent (GP) Intervention Receipt Checklist

At the conclusion of their teaching session, all participants will complete a treatment receipt checklist exploring adequacy of content covered.

	0 = not covered	1 = covered somewhat – but would have liked more information about this	2 = covered completely
What is T1DM			
What is insulin			
What is glucagon			
Use of a glucose monitor			
Preparing glucagon			
Administering glucagon			
Signs and symptoms of hypoglycemia			
Causes of hypoglycemia			
Actions to take when hypoglycemia is suspected			
Treatment for hypoglycemia			
The differences between mild, moderate and severe hypoglycemia			
When blood glucose levels would be rechecked after hypoglycemia			

When a snack of complex carbohydrates should be used in the presence of hypoglycemia			
When to make adjustments to the daily diabetes regimen to correct a pattern of hypoglycemia			
When to use glucagon			
Side effects of glucagon			
When to call the diabetes care team			
The goal target range for your grandchild's blood glucose levels			

Appendix N
GPETS-D Study Advertisement

Grandparents of Grandchildren with Type 1 Diabetes (T1DM)
are invited to participate in a research study called
Grandparent Education through Simulation – Diabetes (GPETS-D)
The purpose of this study is to explore using a new method of teaching T1DM
information and skills to grandparents of grandchildren with T1DM

Participating grandparents attend one introductory meeting in their home (or a place convenient to the grandparent), followed by one 90-minute educational session with a certified diabetes educator at the University of MA Pediatric Endocrinology clinic. All grandparents complete two sets of written forms (one set at the introductory meeting, and a second set sent in the mail). Some grandparents will be invited to complete a telephone interview at the end of the study.

Grandparents will be enrolled for no more than 8 weeks. Grandparents will not be charged for taking part in the research. All grandparents enrolled in the study receive a $25.00 gift card. Grandparents also completing the phone interview receive an additional $15.00 gift card.

Grandparents are eligible to participate in this study if they:

- Are 21 years or older, able to communicate in English, and able to provide consent
- Have a grandchild (aged 12 or younger) diagnosed with T1DM for at least 2 months
- Have a history of babysitting this grandchild prior to the child's diagnosis with T1DM
- Have not previously participated in the October 2012 UMASS GSN Grandparent of Grandchild with T1DM Focus Group Study

Grandparents are not eligible to participate in this study if they:

- Have T1DM or actively manage another's T1DM
- Are unable to babysit their grandchild due to the grandchild having another serious diagnosis other than T1DM

If you are interested in receiving more information about enrolling in this study, please contact Laura Maguire at 1-508-981-1932, LauraLynn.Maguire@umassmed.edu, or at the University of Massachusetts – Worcester, Graduate School of Nursing, 55 Lake Avenue North, Worcester, MA, 01655.

 Insert Docket #_____   Insert Fact Sheet Version # or Date_____

Executive Summary

This descriptive research explored the feasibility of using human patient simulation (HPS) to educate GPs of grandchildren with T1DM in T1DM management. Johnson's interpretation of Leventhal's theory of self-regulation (Johnson, 1999) guided this study's aims, design, sampling frame, data analysis, and the interpretation of results. This two-phased study utilized a mixed method design. In the 1st Phase of this study, researchers conducted preliminary focus groups to inform modification of the Parent Education through Simulation – Diabetes (PETS-D) T1DM teaching intervention for grandparent use.

The 2nd Phase of this research was the 2-group Feasibility Study. GPs were randomly assigned to either an experimental HPS-taught group or a control non-HPS-taught group. GPs completed the Diabetes Awareness and Reasoning Test (DART), Self-Efficacy Diabetes (SED), and Hypoglycemia Fear Survey (HFS) psychosocial measures before (Time 1) and after (Time 2) receiving their designated teaching intervention. Purposefully selected grandparents who scored highest and lowest on the baseline hypoglycemia fear survey were invited to participate in post-intervention qualitative interviews (Time 3).

1. 4/23/15: "At the completion of the GPETS-D study, interested GPs who participated in preliminary focus groups or were randomized to the non-HPS group were offered HPS instruction" was added to the study plan. Four GPs attended this optional HPS T1DM education .

2. 4/23/15: "Participation in the preliminary focus group study" was added to the exclusion criteria.

3. 5/3/14: Changed Appendix G, Step C, to read "you will be enrolled for approx 8 weeks".

4. 5/5/14: Added CDE Assessment of Observed T1D Management Fear to Appendix K to compare CDE observed fear rating with GP HFS score for qualitative interview purposive selection.

5. 6/26/14: Due to preliminary data from the PETS-D parent study, an ISP Modification was submitted to IRB eliminating the FaMM Scale from the GPETS-D study.

6. 11/2/14: The PI observed 20% ($N = 4$) of total sessions ($n = 2$ experimental, $n = 2$ control).

7. 11/22/14: Clarification made that highest and lowest Time 1 HFS scores will be used to determine which GPs are invited to participate in post-intervention qualitative interviews.

8. 1/30/15: Because missing data was minimal, missing Time 2 measure scores for 3 participants (10%) will not be included in analysis (differs from proposed Time 1 data being carried forward to Time 2).

9. 2/11/15: Due to only two quantitative data collection time points, ANCOVA was used to examine the differences (time x group) in total DART, SED, & HFS scores, in place of proposed repeated measures ANOVA.

10. 3/30/15: In view of the feasibility nature of the study, additional analyses were conducted to examine change in all grandparents taught by CDEs from Time 1 to Time 2. Paired sample t-tests were used to compare mean differences in psychosocial outcomes from Time 1 to Time 2 for all participants (without regard for HPS vs. non-HPS group assignment).

11. 6/17/15: To accommodate journal manuscript length limitations, the decision to present quantitative results and qualitative findings separately was made.

12. 6/27/15: Continuous variables lacking normal distribution based on Fisher's measure of skewness were assessed using Mann-Whitney U test, rather than Pearson's Chi-square.

**Educating Grandparents of
Grandchildren with
Type 1 Diabetes (T1D) using
Human Patient Simulation (HPS)**

Laura Maguire RN, MS
University of MA - Worcester
Graduate School of Nursing
PhD Program
May 2015

Background & Significance

- 1 in 400 U.S. children are reported to have T1D [1]

- Parents report a lack of caregiving support due to T1D management complexity [2-5]

- Grandparents (GPs) are an important source of caregiving support for parents of children with T1D [6]

- Parents of children with T1D are typically responsible for teaching GPs the child's care [7]

Background & Significance:
October 2012: Focus Groups (N = 19)

Grandparent Focus Group Recommendations:

- Provide written materials prior to T1D teaching session

- Offer teaching 2 months post-diagnosis

- Extend session length to 90 minutes

- Focus on hypoglycemia management

Grandparent Education through
Simulation (GPETS-D)

The purpose of this study was to explore the feasibility of adapting the PETS-D parent teaching intervention for use with GPs

Specific Aims

Specific Aim 1: Explore the feasibility of implementing an HPS intervention to teach T1D management to grandparents, including to:

- Explore recruitment & retention

- Compare differences in functional & emotional response between experimental & control groups

- Develop and test an intervention fidelity plan

Specific Aims

Specific Aim 2: Explore grandparent learning experiences, using post-intervention phone interviews, including:

- Receptivity to HPS

- Perceived participant burden

Theoretical Framework

Self-Regulation Theory guided this study [8-9]
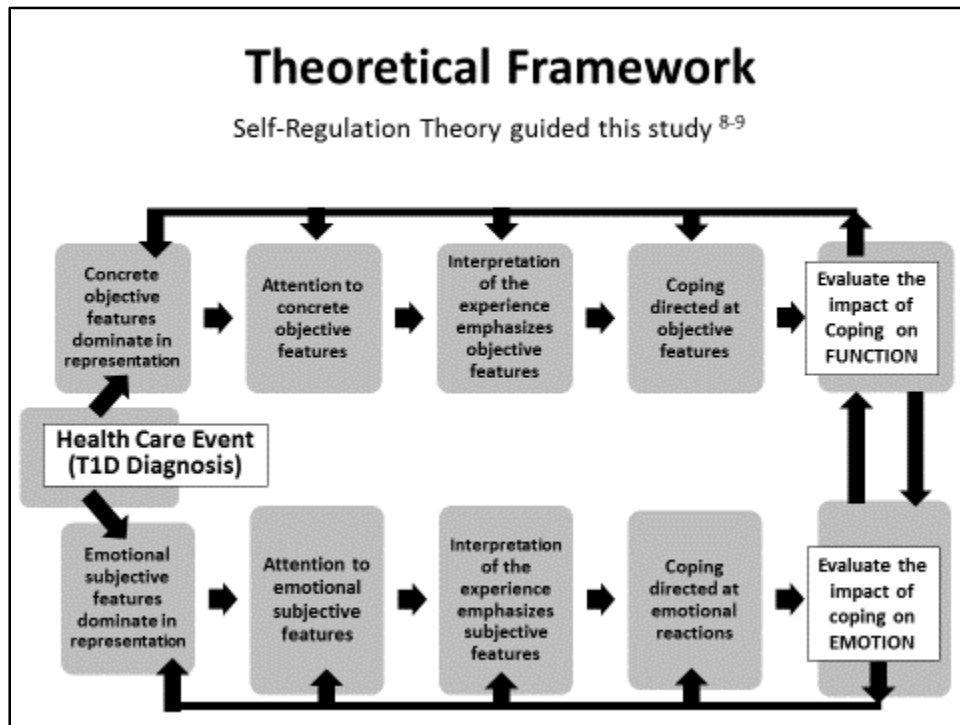
Design: 2-Group Feasibility Study

■ **Experimental HPS Intervention Group**

With GPs in the experimental group, the certified diabetes educator (CDE) reviewed the teaching scenario, using HPS
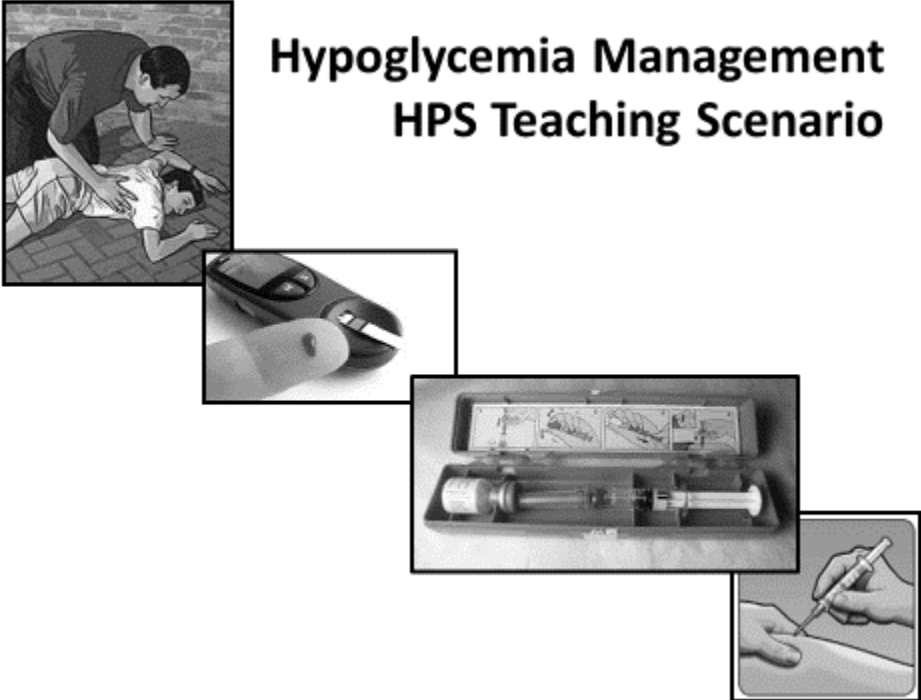
■ **Control NON-HPS Education Group**

With GPs in the control group, the CDE reviewed the same teaching scenario, without using HPS

Hypoglycemia Management
HPS Teaching Scenario

Hypoglycemia Management
Non-HPS Teaching Scenario

Recruitment
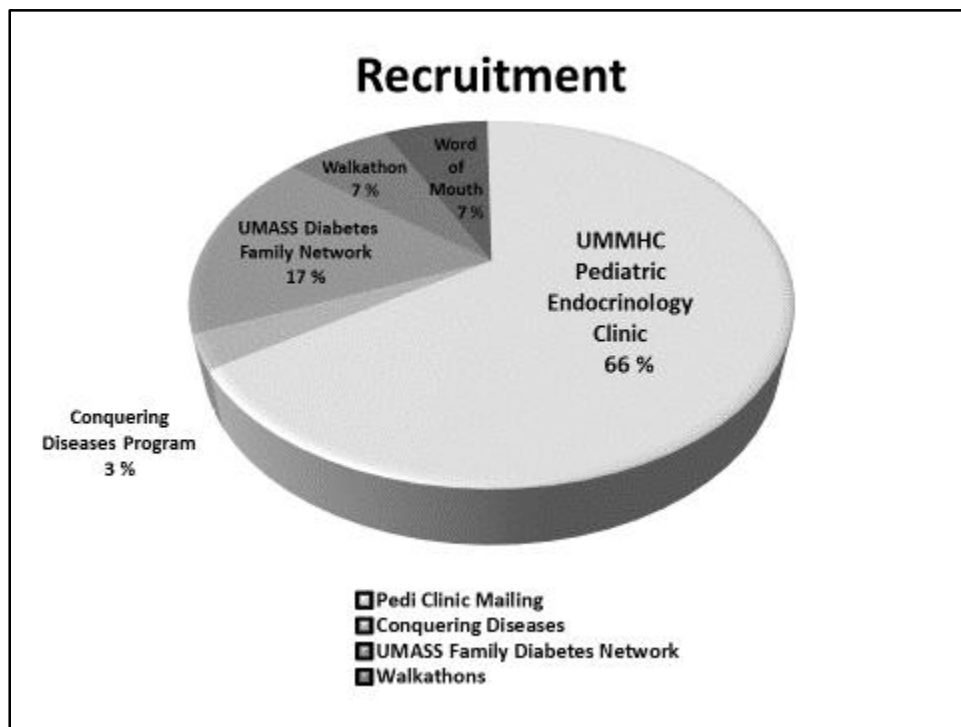
Study Criteria

Inclusion Criteria

- GP to a grandchild, age ≤ 12
- T1D diagnosed ≥ 2 months
- Communicates in English
- History of babysitting this child

Exclusion Criteria

- Grandchild with T1D has serious co-morbidity
- GP has or actively manages another's' T1D
- GP Focus Group participant

Sample

30 Participants were recruited and randomly assigned to the HPS or a Non-HPS group

3 Grandparents Withdrew (10%)

27 Grandparents Completed Participation (90%)

HPS *n* = 1

Non-HPS *n* = 2

HPS *n* = 13

Non-HPS *n* = 14
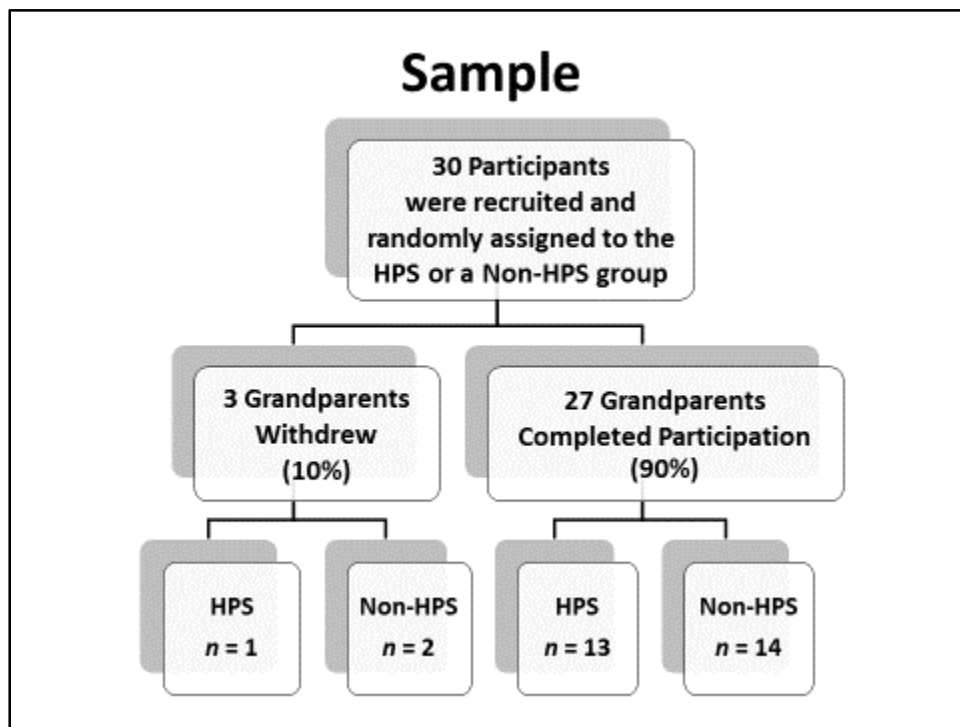
Quantitative Results (Aim 1)

Grandparent Characteristics

N = 30	Frequency (%)
Gender	
Male	11 (36.7)
Female	19 (63.3)
Marital Status	
Married	24 (80)
Divorced/Separated	5 (16.7)
Widowed	1 (3.3)
Employment	
Full-time	13 (43.3)
Part-time	2 (6.7)
Retired /Unemployed	15 (50)
Residence	
Suburban	15 (50)
Rural	15 (50)
Race	
Caucasian	30 (100)

Grandparent Characteristics
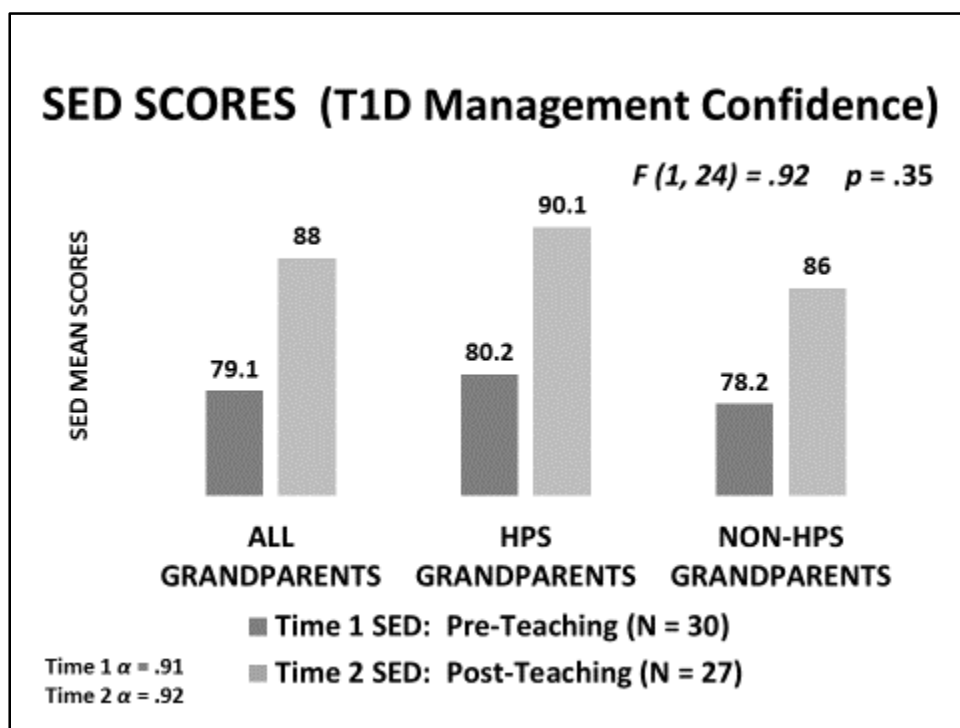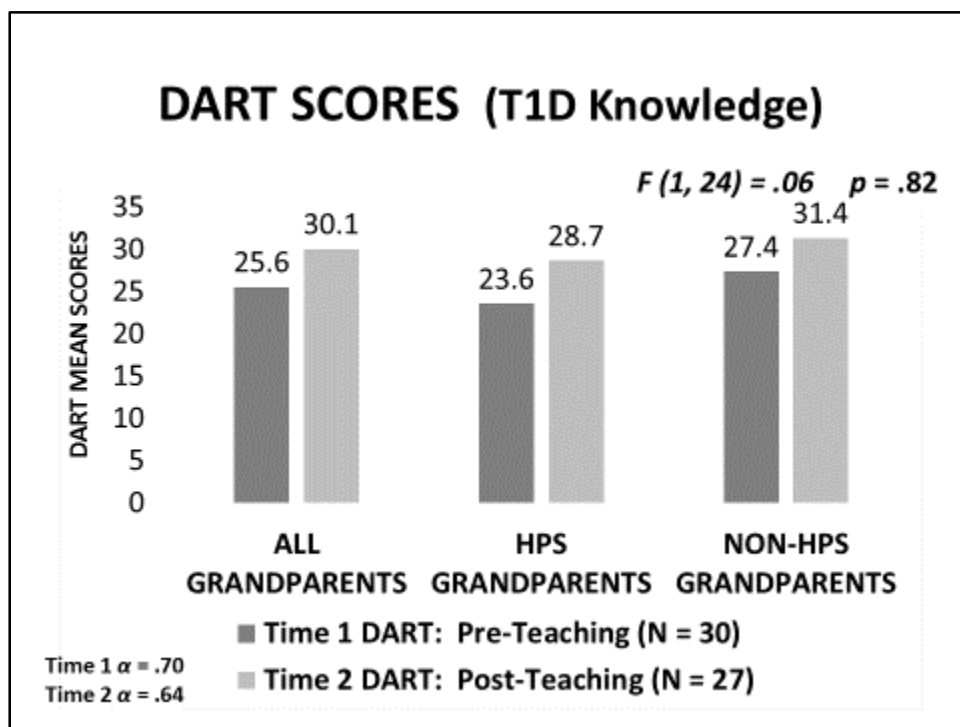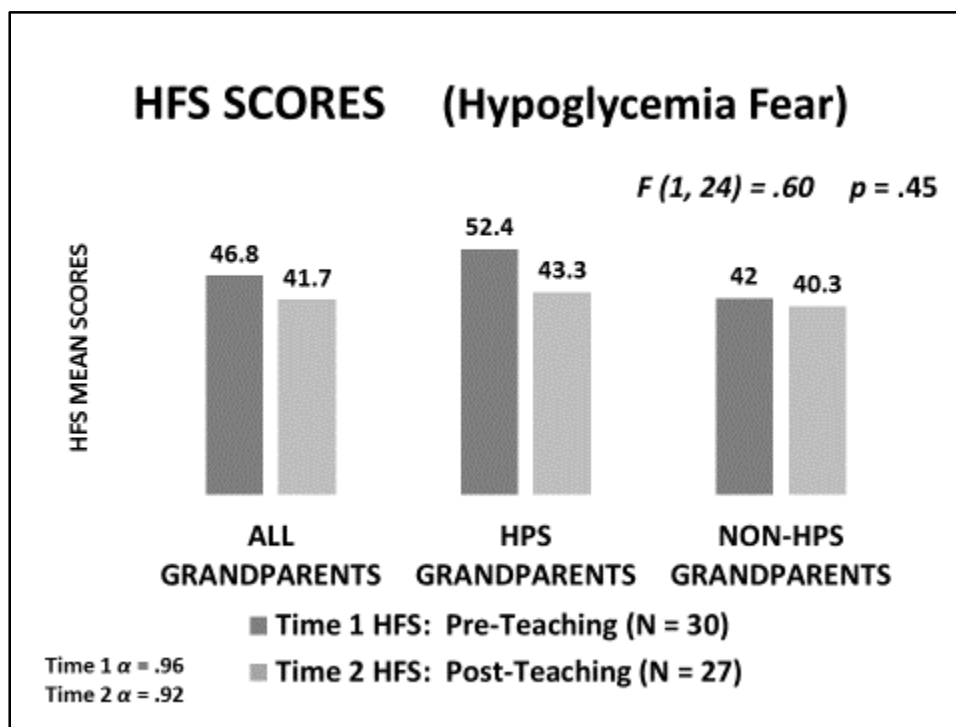
N = 30	Mean (SD)
Age	63.3 (7.3)
Age at Onset of Grandparenthood	52.9 (5.8)
Education Years	14.3 (2.3)
Weekly Babysitting Hours Post-T1D Diagnosis	5.9 (9.4)

Grandchild Characteristics

N = 30	Mean (SD)
Current Age	6.8 (3.1)
Age at Diagnosis	5.4 (3.0)
Multi-dose Insulin	
Yes	20 (66.7)
No	10 (33.3)
Insulin Pump	
Yes	10 (33.3)
No	20 (66.7)
Continuous Glucose Monitor	
Yes	12 (40.0)
No	18 (60.0)

DART SCORES (T1D Knowledge)

F (1, 24) = .06   p = .82

Time 1 α = .70
Time 2 α = .64

■ Time 1 DART: Pre-Teaching (N = 30)
■ Time 2 DART: Post-Teaching (N = 27)

SED SCORES (T1D Management Confidence)

F (1, 24) = .92   p = .35

Time 1 α = .91
Time 2 α = .92

■ Time 1 SED: Pre-Teaching (N = 30)
■ Time 2 SED: Post-Teaching (N = 27)

HFS SCORES (Hypoglycemia Fear)

$F (1, 24) = .60 \quad p = .45$

HFS MEAN SCORES

	ALL GRANDPARENTS	HPS GRANDPARENTS	NON-HPS GRANDPARENTS
	46.8 / 41.7	52.4 / 43.3	42 / 40.3

■ Time 1 HFS: Pre-Teaching (N = 30)
■ Time 2 HFS: Post-Teaching (N = 27)

Time 1 α = .96
Time 2 α = .92

Improved Knowledge and Confidence, Less Fear

Outcome Measures (N = 27)	Time 1 Mean (SD)	Time 2 Mean (SD)	Time 2 minus Time 1 Mean (SD)		CI	t	df	p =
DART	25.2 (4.7)	30.1 (3.7)	+ 4.9	(3.2)	(3.6, 6.1)	8.00	26	.000
SED	78.0 (13.5)	88.0 (10.0)	+ 10.0	(11.4)	(5.5, 14.5)	4.59	26	.000
HFS	47.6 (23.4)	41.7 (17.3)	- 5.9	(14.1)	(-11.5, -.3)	-2.17	26	.040

Teaching Session Length in Minutes

p = .008

NON-HPS
SESSION
LENGTH
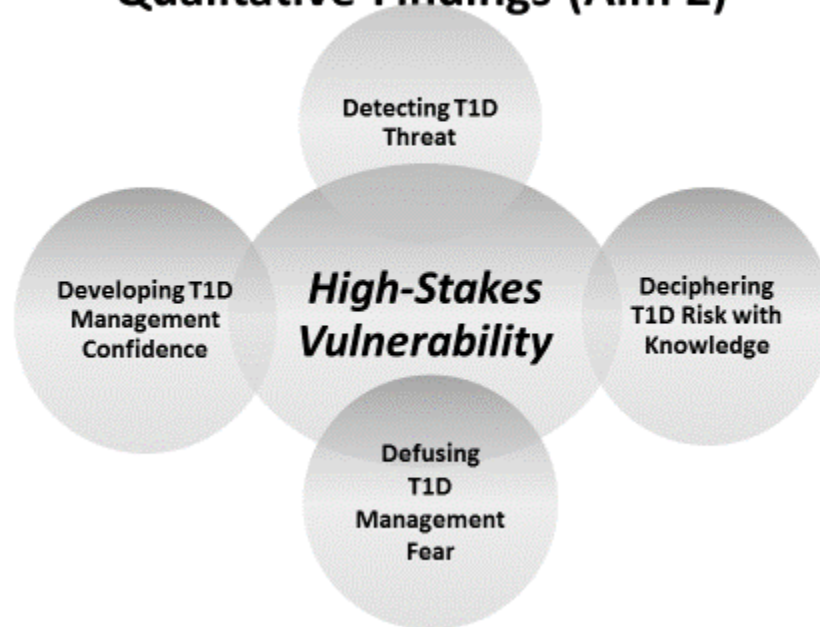77.8 MINUTES

HPS SESSION
LENGTH
88 MINUTES
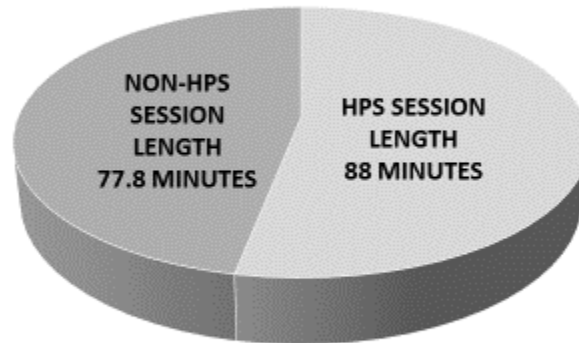
- Non-HPS Session Length in Minutes
- HPS Session Length in Minutes

Qualitative Data Collection & Analysis

- **Post-teaching Telephone Interviews**

  - *N* = 12 (6 HPS GPs & 6 Non-HPS GPs)

  - Interviewed GP's purposefully selected by highest & lowest baseline fear scores

  - Semi-structured open ended questions

  - Non-audio recorded

Qualitative Findings (Aim 2)

Detecting T1D Threat

Developing T1D Management Confidence

High-Stakes Vulnerability

Deciphering T1D Risk with Knowledge

Defusing T1D Management Fear

HPS Teaching Knowledge Gain

"I'm a more "hands-on" than "book" person. I learned more by doing. To touch, feel, and do added much! [I learned…] how to better understand the difference between treating mild and severe hypos. I support [GPETS-D] 100%. It is life-saving. I could not do it [manage hypo's/give glucagon] before [GPETS-D]! " HPS GF

Non-HPS Teaching Knowledge Gain

"[Post-Teaching] I talked with my daughter about everything we went over, including glucagon – she said they had already told me all about the glucagon. I didn't remember anything my daughter had told me. When the CDE discussed [glucagon]–it stuck. When my daughter told me it didn't stick. It was so much so early on [to learn from daughter post-diagnosis]!" Non-HPS GM

Defusing T1D Fear with CDE Teaching

"Basic instruction makes you comfortable…. We are a lot more comfortable [Checking FSBS]…. The more you go over, particularly in a panic situation, a stressful situation, the more you feel like 'I got this'." HPS GM

"I learned if it happens [severe hypoglycemia] it's not DANGER – DANGER - DANGER right away… There were things you could do. I learned what these things were. I also learned that most people don't have these severe lows." Non-HPS GM

Developing T1D Management Confidence

"Now, I'm building on [GPETS-D]. We got a glucometer and I tested myself every day.... After [GPETS-D], I said to my grandchild, 'Can I do the FSBS?', I thought 'I can do this'. It taught me. I feel like a "pro" at [FSBS] now." HPS GF

"[The teaching] made you realize it [T1D] is manageable. With education, you can take care of [T1D]. I felt good, I felt confident! It takes the fright away!" Non-HPS GM

Critical Importance CDE Interaction

"I was impressed with the CDE, she had a confident and competent manner.... I came prepared with questions, but [the CDE] covered it all, I didn't even have to ask!" HPS GF

"Rewarding, especially the CDE visit. I had a person there to ask questions & discuss concerns.... Personal, Face-to-face, there is nothing I would change about it." Non-HPS GM

Limitations

- Study participants were well-educated, residing in rural and suburban areas, and exclusively Caucasian

- Indirect recruitment prevented access to demographic data for eligible GPs who:
  - Were not told about the study by their adult children
  - Chose not to initiate contact with the PI

- Visualizing the glucagon kit may have introduced a dose of the active experimental ingredient to some NON-HPS GPs

Implications for Diabetes Educators

- Early multi-method CDE T1D education is an important point of entry for inducting GP members onto the child's diabetes care team.

- Formal CDE-provided grandparent T1D management education has potential to provide families with additional respite caregiving support.

Research Implications

- Future research could include a collaborative effort, between DNP & PhD prepared nurses, developing, implementing, and measuring program outcomes of a grandparent caregiver T1D education program at UMMHC

Policy Implications

- On April 16th, 2015, the President signed into law a 2 year continuation of H.R. 02; The 'Medicare Access and CHIP Reauthorization Act of 2015'.

- H.R. 02 includes $150 million/year in funding for the Special Diabetes Program (SDP)

- SDP funds NIH diabetes research, and is helping researchers understand pancreatic beta cell biology

- Equally important to direct a portion of SDP funding to psychoeducational nursing research

Conclusion

- Adapting the PETS-D for use with GPs is feasible
  - GP recruitment and retention is feasible
  - GP T1D knowledge, management confidence, and fear scores improved with multi-method CDE-provided T1D teaching
  - Intervention fidelity was maintained
- GPs were receptive to HPS
- GPs perceived minimal participant burden

Questions?
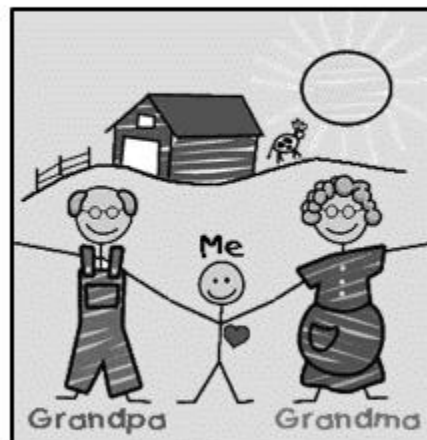
Funding

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- Fairlawn Scholarship

- Charles D. Baker Scholarship

- Sigma Theta Tau, Iota-Phi-at-Large, Research Scholarship

- NIH; NINR:1RO1NR011317: Parent Education through Simulation – Diabetes (PETS-D)

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- Dr. Leslie Soyka, Medical Director of UMMHC Pedi Endo Clinic
- UMW GSN Faculty and Fellow Students
- UMMHC Colleagues
- Dr. Bob Dumas, Beloved Friends, and Peeps
- Frank

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Dissemination Plan

A scientific poster abstract, #723: *Adapting a Parent Diabetes Education Intervention for Grandparents using Focus Group Data*, of the Phase 1 Focus Group Data of this dissertation work was presented on 4-18-13 at the Eastern Nursing Research Society 25th Scientific Sessions, Boston, MA. An oral paper presentation, #0266: *Adapting a Parent Diabetes Education Intervention for Grandparents using Focus Group Data*, of the Phase 1 Focus Group Data of this dissertation work was presented on 6-19-13 at the 11th International Family Nursing Conference, Minneapolis, MN. The primary description of this dissertation work was submitted as a manuscript on July 11, 2015 to *The Diabetes Educator* for review and consideration for publication.