PARENT HEALTH LITERACY AND COMMUNICATION WITH DIABETES
EDUCATORS IN A PEDIATRIC DIABETES CLINIC:
A MIXED METHODS APPROACH

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Abstract

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The association between low health literacy and poor patient-provider communication has been well established in adult patients. No pediatric research has been reported on the relationship between parent health literacy and parent-provider communication. This mixed methods study examined and explored how parent health literacy affected the communication process with diabetes educators in a pediatric diabetes clinic.

This study used the Conceptual Framework of Provider Patient Communication as a theoretical framework. Health literacy was measured with the Rapid Estimate of Adult Health Literacy in Medicine. Quality of communication was assessed with quantitative and qualitative methods using 5 subscales of the Interpersonal Processes of Care Survey and semi-structured interviews. A convenience sample of 162 parents attending Diabetes Clinic with their child completed the survey and a

subsample of 24 parents (13 adequate health literacy/11 low health literacy) participated in a semi-structured interview.

Eighteen and a half percent of parents were assessed as having low health literacy. Parents' report of poor communication ranged from 6-38% across the 5 Interpersonal Processes of Care subscales (general clarity, explanations of diabetes, explanations of diabetes care, eliciting concerns, decision-making). Statistical analyses found a positive association between health literacy and general clarity but no associations between health literacy and the four other communication outcomes. Directed content analysis of interviews revealed the similarities and differences for communication processes for parents with low and those with adequate health literacy. Parents with low health literacy were confused with diabetes jargon and wanted information to be communicated in simple language, broken down into key points and repeated. Low health literate parents preferred hands-on teaching strategies. Parents with adequate health literacy wanted comprehensive information, provided at a parent-driven pace, and communicated through ongoing dialogue. All parents discussed the need for diabetes educators to understand their other life stressors and to have an encouraging tone during interactions. These findings suggest that diabetes educators need

training in clear communication techniques and teaching strategies, and should develop learner-driven, problem-based diabetes curriculums.

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Chapter 1

Introduction

Parents of children with type 1 diabetes assume much of the responsibility of diabetes care for their child, relying on face-to-face communication with a diabetes educator to learn the decision-making and psychomotor skills of diabetes management. Yet, 22% of parents of children with special health care needs reported that health care providers did not explain things in ways that were understandable (Miller, Macon, Gaboda, & Cantor, 2012). Evidence suggests a positive correlation between the ability to understand oral communication and individuals' health literacy skills to obtain, process, and understand health information (Doak, Doak, Friedell, & Meade, 2008). For instance, the quality of communication improved for adult patients with diabetes as health literacy levels increased (Schillinger, Bindman, Wang, Stewart, & Piette, 2004). Conversely, studies with adults suggest that poor quality of patient-provider communication has been associated with limited health literacy, i.e. low literate patients are more likely to not understand words used or explanations given by the provider (Castro, Wilson, Wang, & Schillinger, 2007; Sudore et al., 2009).

Little is known about the effectiveness of provider communication for parents with varying health literacy skills. A concurrent mixed methods study was undertaken to examine and explore how the process of communication between diabetes educators and parents in a pediatric diabetes clinic changes

with the level of parent health literacy. Findings from this study provided insight into parents' perceptions of communication with diabetes educators and hope to inform the professional development of diabetes educators.

This chapter describes background information on pediatric diabetes, the communication process, and the effects of health literacy on communication. The Conceptual Framework of Professional Patient Communication and the Interpersonal Processes of Care in Vulnerable Populations Framework are discussed to establish a theoretical context for the study. The chapter concludes with the research purpose and aims, and the assumptions of the study.

Background and Significance

Approximately 215,000 U.S. children below the age of 20 years have diabetes (Centers for Disease Control, 2011) with estimates that 80% of pediatric cases are children with type 1 diabetes (Dall et al., 2010; Liese et al., 2006). Currently 1 in 400 children and adolescents live with diabetes (Centers for Disease Control, 2011). The number of new cases of type 1 diabetes is inexplicably rising each year (Lipman, et al., 2013; SEARCH Study Group, 2004) with the number of new cases for children under 5 years old predicted to double by 2020 (Patterson & Dahlquist, 2009).

Medical expenses for patients with diabetes are more than 2 times higher than for patients without diabetes with the annual cost of type 1 diabetes estimated at \$14.9 billion dollars (Dall et al., 2010). The economic burden per

case for type 1 diabetes is higher than for patients with type 2 diabetes; pediatric diabetes-related costs average \$4,730 per person-year (Ying et al., 2010) rising to an average of \$14,856 in adulthood because of diabetes complications (Dall et al., 2010). Effective communication remains a challenge to teach parents to manage their child's diabetes at near normal blood glucose levels to reduce the risk of micro- and macrovascular complications and the associated rise in cost (ADA, 2010; Nathan et al., 2005).

Diabetes educators are largely responsible for educating parents to have the knowledge and skills to manage their child's diabetes. In group classes and individual sessions in clinic, diabetes educators teach and reinforce an intensive regimen involving frequent blood glucose monitoring, detailed carbohydrate counting, regular exercise, insulin dose adjustment, and management of acute episodes of hypoglycemia and hyperglycemia (Haas et al., 2013). Studies in adults have found that routine care with diabetes educators has been associated with improved self-care (Bundesmann & Kaplowitz, 2011) and lower health care utilization costs (Duncan et al., 2009).

Patient-Provider Communication

Patient-provider communication is essential to quality care yet research shows that many providers use medical jargon and fail to explain conditions and care in ways that are understandable (Castro, Wilson, Wang, & Schillinger, 2007). Healthy People 2020 and the National Action Plan to Improve Health

Literacy advocate that all people have the right to health information provided in clear, understandable terms (DHHS, 2010a). Rubin (2012) advocates for the “listenability” of oral health messages, akin to the readability of print materials that are easier for patients and their families to hear and comprehend. Effective communication is related to increased patient satisfaction (Beckett, Elliott, Richardson, & Mangione-Smith, 2009; Korsch, Gozzi, & Francis, 1968; Nápoles, et al., 2009), increased adherence to medical regimens (Heisler, Bouknight, Hayward, Smith, & Kerr, 2002; Zolnieriek & DiMatteo, 2009), and improved diabetes outcomes (Aikens, Bingham, & Piette, 2005).

Barriers to Communication

Disparities in patient-provider communication may be explained by racial, socioeconomic, and educational factors (DeVoe, Wallace, & Fryer, 2009). Physicians were reported to be less patient-centered and had less positive affect with African American patients compared to White patients (Johnson, Roter, Powe, & Cooper, 2004). Low-income adult patients were less likely to report that providers explained things that they misunderstood (DeVoe, Wallace, & Fryer, 2009). Additionally, patients with less than high school education reported feeling disempowered in their communication with their provider, and were less likely to ask questions for fear of nagging (Brugge, Edgar, George, Heung, & Laws, 2009). In contrast, participants with higher education (at least 2 years college education), reported that their providers expected and answered their questions

with sophisticated information about their health care needs (Brugge et al., 2009).

The health literacy skills of a parent or caregiver may further contribute to disparities in patient provider communication (Sanders, Federico, Klass, Abrams, & Dreyer, 2009). Approximately 1 in 4 parents (Yin et al., 2009) have limited health literacy skills defined as “the degree to which individuals [parents] have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions [for their child] ” (Parker & Ratzan, 2010, p. 20). Persons with limited health literacy are less likely to understand medical terminology (Castro, et al., 2007) or to ask questions (Katz, Jacobson, Veledar, Kripalani, 2007) during a medical encounter. Similar to risks associated with poor communication, limited parent health literacy has been associated with minority race, low educational level, low income, public insurance, and single parenthood (Janisse, Naar-King, & Ellis, 2010).

Communication and Health Literacy

Recent communication and health literacy research has extended beyond functional literacy skills of reading and writing to explore the role oral communication plays in health literacy (Roter, 2011). Although individuals with poor health literacy depend on their provider for health information, they may experience difficulties with communication (Doak, et al., 2008). In a sample of adults with diabetes, patients with low health literacy reported poorer

communication with their clinician than those with adequate health literacy (Schillinger et al., 2004). Specifically, patients with low health literacy were six times more likely to report that their doctor used words that they did not understand and five times more likely to report that their doctor did not give them enough information about their health problems (Schillinger et al., 2004). These substantive differences indicate an extensive miscommunication between providers and patients.

Although these adult data are compelling, very little pediatric research has been conducted exploring the relationship between parent health literacy and parent-provider communication. Most studies have focused on physician communication skills with very little data on the skills of other clinicians. No data on parent perceptions of communication with diabetes educators have been reported. Yet, diabetes educators routinely provide ongoing diabetes education within a pediatric diabetes specialty practice. National recommendations suggest quarterly visits with a diabetes educator for ongoing diabetes education and support at the time of routine checkups (Haas et al., 2013).

Conceptual Framework of Patient Professional Communication

To understand the relationship between the quality of communication processes and parent health literacy, the Conceptual Framework of Patient Professional Communication has been adapted by Howe for use (Feldman-Stewart, Brundage, & Tishelman, 2005). Developed by Feldman-Stewart and

colleagues to understand communication in the oncology setting, the framework is applicable to the communication process that occurs between diabetes educators and parents in a pediatric diabetes setting.

Figure 1: Conceptual Framework of Patient Professional Communication

Feldman-Stewart et al. (2005) describes communication in five components: 1) goals of each participant, 2) attributes of each participant, 3) the environment, 4) external factors that influence attributes, and 5) the process of communication, conveying and receiving of messages.

Goals

Each participant takes part in the communication process with goals or the reasons for communicating. Goals were not measured directly in this study but instead were described and assumed in general terms. Goals for the diabetes educator are described in the standards of diabetes self-management training. Potential goals include but are not limited to teaching meal planning, insulin dose adjustment, exercise management, insulin pump therapy, and management of hypoglycemia and hyperglycemia (Haas et al., 2012). Educator interventions are aimed to educate and support parents to do daily diabetes tasks and problem-solving to maintain tight diabetes control (hemoglobin A1C < 7.5%) to decrease risk of chronic complications. (ADA, 2010; Nathan et al., 2005).

Parents, too, expect education to be a central part of every office visit (Ginsburg et al., 2005). From their interactions with providers, parents want expert medical advice to create a diabetes treatment plan that is integrated into their child's and family's life; parents also want support around basic parenting skills as they raise a child with diabetes (Howe, Ayala, Dumser, Buzby, & Murphy, 2012).

Attributes

Feldman-Stewart et al. (2005) proposes that communication is a function of each participant's attributes. More specifically, five key attributes of individuals are described- needs, skills, values, beliefs, and emotions. These attributes

inform the information giving and relational aspects of how messages are conveyed and received. Attributes are considered amenable to intervention.

Attributes of the diabetes educators were not directly measured although the social context or the culture of medicine was understood to shape the educator's needs, skills, values, beliefs, and emotions. As found in all professional cultures, diabetes educators have a repertoire of terminology and phrases used to communicate about diabetes, treatment goals and outcomes. Working from this dominant medical culture, diabetes educators may be unaware of the mismatch in the ways they teach and the ways parents interpret messages (Fang, Panguluri, Machtinger, & Schillinger, 2009).

Parent health literacy was the attribute of interest in this study. Individuals with low health literacy, in particular, are at risk of being confused during interactions with providers (Fang et al., 2009). Although health literacy is related to the literacy and numeracy skills of the individual, it is more useful to conceptualize health literacy within the contextual demands placed on the individual by the clinical condition, its treatment, and interactions with clinicians (Paasche-Orlow, Schillinger, Greene, & Wagner, 2006).

External Factors

External factors refer to characteristics of the person such as race, age, and socioeconomic status that are not amenable to intervention but are understood to influence each individual's attributes (Feldman-Stewart et al.,

2005). External factors of the diabetes educator were not measured or analyzed in this study. It was recognized, however, that race concordance versus discordance between parents and providers has not been associated with differences in communication experiences (Stevens, Mistry, Zuckerman, & Halfon, 2005). In contrast, language discordance is a substantial barrier to effective communication (Sudore, et al., 2009) but was not explored in this sample of English speaking parents.

Data for external factors including parent-related and child diabetes-related characteristics were collected for this study. Characteristics such as age, education, and race affect the communication process directly. For example, college educated parents are more likely to be assertive with their opinions and ask questions of the provider than their less educated counterparts (Street, 1992). These same characteristics, namely minority race, less than high school education, and low socioeconomic status have been associated with limited health literacy (Yin et al., 2009).

Child diabetes-related characteristics such as the child's duration of diabetes, insulin regimen, and level of metabolic control may influence beliefs and attitudes within the communication process. A child's metabolic control has been found to influence providers' attitudes during clinical encounters with patients and families feeling judged, not supported, and threatened (Howe et al., 2012; Hall, Roter, Milburn, Daltroy, 1996).

Environment

Environment refers to both the physical setting and the local social and cultural context. In this study, the environment referred to a pediatric diabetes specialty practice within an urban, tertiary care pediatric institution. Diabetes visits included a 30 minute appointment with a diabetes educator and a 15 minute consultation with a physician or nurse practitioner at every visit. A dietitian or psychologist were consulted on an as needed basis. Eight diabetes educators (6 full time, 2 part time), with 1-15 years experience, provided the majority of diabetes education to patients and their parents. Six of the educators were certified diabetes educators; the remaining two educators were expected to take the certification exam in the next year. The inpatient health system had provided staff development in health literacy and clear communication techniques but these educators had not participated in any of these trainings.

Communication Process: Conveying and Receiving Messages

Feldman-Stewart et al. (2005, p. 804) describes the giving and receiving of messages as “the heart” of the communication process, depicting the main action in the conceptual framework. Messages back and forth can be verbal or non-verbal, including both information giving and relational components.

Focusing on the information giving aspect of communication, the Interpersonal Processes of Care Framework (IPC) was incorporated to provide further conceptual and operational definitions to the communication process

(Stewart, Nápoles-Springer, & Pérez-Stable, 1999). A review of the communication literature and clinical experience with diverse racial/ethnic and socioeconomic groups inform the operational definitions of concepts in the IPC Survey. Specifically, the quality of communication describes the provider's clarity of messages and explanations of the condition and self-care (messages conveyed from provider to parent), as well as how well the provider elicits concerns and encourages decision-making (messages conveyed from parent to provider) (Stewart et al., 1999). This study used 15 IPC items to measure parents' perceptions of the quality of the communication process (Stewart et al., 1999).

Although the complexity of communication processes are described in Feldman-Stewart's framework (2005), to measure all concepts and relationships among concepts was beyond the scope of this study. This study examined and explored the communication process from the perspective of parents as seen in the adapted framework below. Specifically, the study focused on a parent attribute (health literacy), parent external factors (race, age, income, and education level, and child duration of diabetes and metabolic control), and the quality of communication processes (Appendix A: Table of Variables).

Figure 2: Adapted Communication Framework

Propositions

1. Goals of the educator and parent directly influence the Communication Process
2. External Factors including parent factors and child diabetes related factors influence parent's attributes (needs, skills, values, beliefs, and emotions).
3. Parent Attribute (Health literacy) influences the quality of Communication Processes. As the level of parent health literacy decreases, parent perception of the quality of communication decreases. Conversely, as the level of parent health literacy increases, parent perception of the quality of communication process increases.

Purpose

Informed by the Conceptual Framework of Patient Professional Communication (Feldman-Stewart et al., 2005) and the Interpersonal Processes of Care Framework (Stewart et al., 1999), the overall purpose of this concurrent mixed methods study was to examine and explore how the process of communication between diabetes educators and parents in a pediatric diabetes clinic was affected by the level of parent health literacy.

Research Aims and Hypothesis

Four specific aims of this study were proposed:

1. Determine the prevalence of low health literacy in a sample of parents of children with type 1 diabetes in North Texas.
2. Determine the relationship between parents' perception of quality of parent-educator communication and parent health literacy.
3. Describe parents' experiences of face-to-face communication with diabetes educators and parents with attention to differences by health literacy level.
4. Use the qualitative data to illustrate, corroborate, and help explain the quantitative statistical results of quality of communication as a function of parent health literacy level.

The research hypothesis was that parents with limited health literacy were more likely to report poorer quality of communication processes than parents with adequate health literacy (controlling for race, income, education level, duration of

diabetes, metabolic control). As well, parents with limited health literacy would report different experiences of communication with diabetes educators than parents with higher health literacy.

Essential Assumptions of the Model

The conceptual framework for this study included the following assumptions:

1. Diabetes management is complicated and very demanding on parents.
2. Parents are invested in learning about and performing diabetes care for their children.
3. Diabetes educators have specialized training in diabetes care and patient education and are a primary resource for parents to learn diabetes management of their child.
4. Diabetes educators work within a culture of medicine that has its own medical jargon and focus on pathophysiology that is different than the lay culture of patients and families.
5. Effective communication is critical in diabetes education.
6. Parents can honestly and accurately self-report their perceptions and experiences of communication with diabetes educators.

Conclusion

The adult literature consistently suggests that the quality of patient-provider communication is negatively affected when patients have limited health literacy, confirming the need to explore the impact of parent health literacy on parent-provider communication. The Patient Professional Communication and the Interpersonal Process of Care Frameworks provided a theoretical perspective to explore communication processes between parents of children with type 1 diabetes and diabetes educators in a pediatric diabetes clinic. This mixed methods study examined and explored how parent health literacy affected the communication process.

Chapter 2

Critical Review of the Literature

Effective provider communication has been positively correlated with patient satisfaction (Anderson et al., 2007; Swedlund et al., 2012), self-care (Heisler, Cole, Weir, Kerr, & Hayward, 2007), adherence to treatment (Zolnierrek & DiMatteo, 2009), and health outcomes (Aikens, et al., 2005). Although extensive research has been conducted examining communication processes, less empirical evidence was available on the relationship between patient-provider communication and health literacy. Adult studies have demonstrated an association between poor patient-provider communication and limited health literacy, with low literate adults reporting difficulty with medical jargon, understanding directions for care, and participating in their health care (Castro, Wilson, Wang, & Schillinger, 2007; Katz, Jacobson, Veledar, & Kripalani, 2007; Sudore et al., 2009).

Little research existed on how health literacy affects communication processes in pediatric specialty care. The purpose of this concurrent mixed methods study was to examine and explore how the level of parent health literacy affected the process of communication between diabetes educators and parents in a pediatric diabetes clinic. The quantitative findings provided data on the frequency and magnitude of communication problems and the qualitative

findings added rich description to compare the perceptions of communication processes for parents with low versus adequate health literacy.

The intent of this literature review was to examine current research linking health literacy and communication processes. First, a description of health literacy is offered followed by a discussion of specific aspects of the communication process, highlighting studies that examined the impact of health literacy. Because most research on health literacy and communication processes has been conducted with adult samples, adult data is described; pediatric data when available is also presented. The literature review included searches on a wide variety of databases including CINAHL, Medline, Psych info, Academic Search Complete, and Google Scholar. Search terms included diabetes, child health, patient-provider communication, parent-provider communication, health communication, health literacy, functional health literacy, and interactive/communicative health literacy, health care disparities, knowledge, self-care, and health outcomes.

Health Literacy

Health literacy involves a set of skills needed to negotiate health within the health care environment including print literacy (the ability to read and understand information), numeracy (the ability to use and understand numbers) and oral literacy (the ability to speak and listen) (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). Health literacy is commonly defined as “the degree to

which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Nielsen-Bohlman, 2004; Parker & Ratzan, 2010). Defining health literacy in terms of individual capacity has received criticism, with leaders in the field advocating that health literacy be considered as a function of interactions between the individual and the health care system (Paasche-Orlow & Wolf, 2007).

Prevalence of Limited Health Literacy

Data on the prevalence of limited health literacy varied and was difficult to compare across studies because of differences in sample and literacy measurement methods. Regardless, all estimates of limited health literacy in the U.S. demonstrated a need to understand how low health literacy affected the communication process during health care encounters.

The National Assessment of Adult Literacy Survey (NALS), using a nationally representative sample of 17,000 households, found that half of U.S. adults have poor literacy skills (Baldi, et al. 2009). For the first time, the 2003 NALS also included health literacy statistics, estimating that 75 million or 1 in 3 adults have below basic or basic health literacy skills (Kutner, Greenberg, Jin, & Paulsen, 2006). Individuals with below basic skills range from being illiterate to having the skills to read information in short texts, follow simple instructions, and to circle the date on an appointment slip. Those with basic literacy skills can read

and understand short pieces of information and can give two reasons why a person with no symptoms should get tested for a specific disease from reading a short pamphlet (Baldi,et al., 2009, p.17-10). In another estimate of the prevalence of limited health literacy, Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd (2005) conducted a systematic review of 85 studies to include data on 31,129 subjects, finding that 1 in 4 subjects had low health literacy (< 6th grade skills) and more than half had low or marginal health literacy (< 8th grade or less skills).

In a secondary analysis of data from the 2003 National Assessment of Adult Literacy, Yin et al. (2009) estimated that 1 in 4 parents in the U.S. have low health literacy, a slightly lower prevalence than that found in the general adult population. In comparison, Hassan & Heptulla (2010) reported that 1 in 6 parents of children with type 1 diabetes had limited health literacy. This lower prevalence, equal to half the estimate for U.S. adults, may be due to differences in health literacy measurement or because parents of children with chronic illness have higher levels of health literacy from their experience with health care.

Social Determinants of Limited Health Literacy

Parents of minority race, low education attainment, and low socioeconomic status are most at risk for low health literacy (Janisse, Naar-King, & Ellis, 2010). Parents of Black and Hispanic race/ethnicity were more likely to have low health literacy compared to White parents (Janisse et al., 2010). Low

parental literacy skills has been associated with less than 12th grade education; parents with less than high school education were 8 times more likely to have low health literacy skills than parents with higher education experience (Bennett, Robbins, & Haecker, 2003). Although related, education level may be a poor estimate for health literacy level as 44% of high school graduates and 13% of college graduates have limited health literacy (Kutner, Greenberg, Jin, & Paulsen, 2006, p. 14). Low parental health literacy has been associated with lack of health insurance for the child (Yin et al., 2009) and living in a single parent household (Bennett et al., 2003), both proxies for lower socioeconomic status.

Association of Health Literacy and Health Outcomes

Health literacy, more than race and education, may be an important contributor to disparities in health outcomes (Sentell & Halpin, 2006). Data in adults with diabetes has found that low health literacy has been associated with less diabetes knowledge (DeWalt, Boone, & Pignone, 2007) poorer diabetes self-care (Cavanaugh et al., 2008), worse diabetes control (Powell, Hill, & Clancy, 2007) and a 2-fold increase in retinopathy complication (Schillinger et al., 2002).

Parent Health Literacy and Diabetes Outcomes

Evidence on the relationship between parent health literacy and diabetes outcomes for their children has been mixed. Hassan & Heptulla (2010) found that children of parents with inadequate health literacy had significantly poorer diabetes control compared to those with parents with adequate health literacy

(hemoglobin A1C 10.4 % vs. 8.6% respectfully, $p < .001$). In contrast, in a cross sectional study examining mediator variables between literacy and diabetes control, DeWalt et al. (2007) found no relationship between health literacy and hemoglobin A1C levels, suggesting a weaker relationship. This study, however, included many mediator variables such as self-efficacy, trust, knowledge, and decision making, and may have been statistically underpowered.

Measurement of Health Literacy

The Rapid Estimate of Adult Literacy in Medicine (REALM) (Murphy, Davis, Long, Jackson, & Decker, 1993) is the most commonly used instrument in health literacy research and has been used to measure parent health literacy (DeWalt, Dilling, Rosenthal, & Pignone, 2007; Yin, Dreyer, Foltin, van Schaick, & Mendelsohn, 2007). The REALM focuses on basic reading and writing skills, measuring functional health literacy. Although limited in its ability to measure oral health literacy skills to seek, understand, and use health information (Berkman et al., 2011; Jordan, Buchbinder, & Osborne, 2010), assessments of low functional health literacy may be a marker for communication problems beyond reading ability (Schillinger et al., 2003) The REALM has been used in health literacy and communication research and was used to assess health literacy of parents in this study.

Patient-Provider Communication

Communication during medical consultation has been defined as a transactional process including both information-giving and relational aspects (Makaryus & Friedman, 2005; Ong, De Haes, Hoos, & Lammes, 1995; Tates & Meeuwesen, 2001; Watson, Kieckhefer, & Olshansky, 2006). The information giving aspect of communication relies on provider skills to use clear language to provide practical and useful information while relational aspects requires listening and empathic skills (Makaryus & Friedman, 2005; Swedlund et al., 2012). This study focused on parents' perception of the information giving aspects of the communication process between diabetes educators and parents including the educators' general clarity of messages, explanations of diabetes and its management, elicitation of concerns, and decision-making.

Communication Process: General Clarity

Clear communication depends on the ability of clinicians to use vocabulary that is familiar to the patient, to speak clearly and slowly, and to confirm patient comprehension (Bennett, Switzer, Aguirre, Evans, & Barg, 2006; Stewart, et al., 1999). Parents who reported always understanding how their provider answered their questions were three times more likely to be satisfied with care (Hart, Kelleher, Drotar, & Scholle, 2007). Yet, health care providers use extensive medical jargon during clinical encounters. From an analysis of audiotaped diabetes visits with adult patients, providers used medical jargon an average of 4

times per visit with 29% of the jargon used when providing health education (Castro et al., 2007). Patients struggling to understand medical jargon were unlikely to admit this to the clinician (Bennett et al., 2006)

Early communication research demonstrated that patients often misunderstood medical terms or confused its meaning with more common lay definitions. For example, Hadlow & Pitts (1991) found that 77% of 117 adult patients being treated for hypertension reported that they had Hyper-Tension, a state of extreme anxiety characterized by a state of being hyper-tense.

More recently, two collaborating studies have examined how limited health literacy affects patients' understanding of medical jargon. First, Schillinger, et al. (2004), in a large cross sectional study with adult diabetes patients (N=408), found that patients with low health literacy were six times more likely than those with adequate health literacy to report that their doctor used words that they did not understand. Second, Castro et al. (2007) audio recorded medical encounters with a subset of the original sample including 74 participants who had limited health literacy. Transcripts were analyzed for medical jargon and telephone interviews were conducted to explore participant's understanding of diabetes-related jargon. Participants were presented with 18 diabetes-related jargon terms, one of which was obtained from the patient's own audio taped visit. Jargon terms were stated to the patient both alone and within a sentence context transcribed from the audiotapes; example jargon terms included "weight is stable,

hemoglobin A1C, and dialysis,” (p. S91) expressions used every day by diabetes clinicians. Rating their understanding on a 4-point Likert scale from no understanding to total understanding, more than 60% of low literate participants had little or no understanding of the terms and could not define the jargon term (Castro et al., 2007). Instead, when asked to explain “dialysis” in their own words, some patients responded with “check something every day,” confusing the word “dialysis” with “daily”, a word heard and used commonly in lay conversations (Castro et al., 2007).

These adult studies demonstrate a substantial mismatch between provider communication and patient comprehension. Study samples included older, low income, primarily non-White adults with a high school education or less, recruited from primary care or internal medicine clinics located in an urban, public hospital. Inadequate health literacy level was relatively high in these patient samples. The magnitude of miscommunication for adults with low health literacy confirmed the need to study the impact of parent health literacy on communication with providers in a pediatric clinic. Pediatric diabetes, however, is commonly treated by an interdisciplinary team within a specialty practice. It remained unknown if low literate parents of children with type 1 diabetes would report a similar degree of miscommunication.

Communication Processes: Explanations of Condition and Diabetes Care

Successful diabetes education depends on effective communication between providers and patients and families about diabetes, insulin regimens, symptoms, side effects, and test results. The health care provider's ability to engage in effective communication promotes or discourages the ability to manage and to live well with diabetes (Thorne, Harris, Mahoney, Con, & McGuinness, 2004). In adult studies, high rating in patient-provider communication has been significantly associated with better self-care of diabetes (Heisler, Bouknight, Hayward, Smith, & Kerr, 2002; Piette, Schillinger, Potter, & Heisler, 2003), treatment adherence (Zolnieriek & DiMatteo, 2009) and better glycemic control (Aikens et al., 2005). Because most children with type 1 diabetes are diagnosed at a young age, parents assume much of the responsibility for daily diabetes care for the child (Wysocki et al., 2009).

Evidence suggests that patients recall only a small portion of health information delivered in a clinical encounter. Less than half of adult patients at discharge from the hospital were able to report their diagnoses or the name, purpose, or side effects of their medications (Makaryus & Friedman, 2005). In a seminal pediatric study to determine how many recommendations children and parents remembered from routine diabetes visits, Page, Verstraete, Robb, & Etzwiler (1981) found that parents recalled only 2 out of 7 recommendations related to glucose monitoring, diet, insulin regimens, and injection technique.

Poor recall of information suggested a missed opportunity for provider communication perhaps related to lack of clarity or overloading of information.

A few studies have examined how patients with low health literacy interpret provider communication about their condition or care. In a study with adult patients with diabetes, participants with low health literacy were five times more likely to report that they did not understand explanations of their condition provided by their doctor than those with adequate health literacy (Schillinger et al., 2004). Pooling data across three studies to include 771 adults with either diabetes or a cardiac condition, Sudore et al. (2009) reported that patients with low health literacy were two times more likely than those with adequate health literacy to report feeling confused about their medical care because the doctor did not explain things well. Of note, items from the Interpersonal Processes of Care Survey (IPC) were used in both of these studies (Stewart, Napoles-Springer, & Perez-Stable, 1999). Schillinger (2004) retained all items while Sudore (2009) used a small subset of 4 items. Although the 4 items used in the Sudore study have been adopted by the Agency of Health Care Quality and Research to assess health care quality (AHRQ, 2008), the condensed IPC items may not be as sensitive as the original IPC instrument, explaining why more substantial differences were found in the Schillinger study.

While these first two studies examined how health literacy affected participants' reported understanding of explanations by their provider, a third

study examined if patients' health literacy level influenced how they understood their prescribed self-care. In a study conducted with patients in a stroke clinic, Fang, Panguluri, Machtinger, & Schillinger (2009) found that a greater percentage of subjects with inadequate health literacy compared to those with adequate health literacy were unable to describe the indication for taking Warfarin (50 % vs. 23.1%, $p < 0.01$) or to describe the signs and symptoms of stroke (64.5% vs. 17.3%, $p < 0.01$).

Communication Processes: Eliciting Concerns and Decision-Making

Providers play a critical role in encouraging patients to feel empowered to seek information, to ask questions, and to actively participate in their health care. In adult patients with diabetes, higher ratings of participatory decision-making style and provider communication effectiveness were associated with higher reports of self-management of diabetes (Heisler et al., 2002). In pediatric care, parents reported the highest satisfaction with their provider and their child's health care when they were asked about their own ideas in regards to their child's health indicating a communication style of collaboration and mutual understanding (Hart et al., 2007). Similarly, from a qualitative study, parents felt empowered when their understanding of and competence in their child's diabetes care was acknowledged during the diabetes encounter, demonstrating a mutual respect for each other's expertise (Howe, Ayala, Dumser, Buzby, & Murphy, 2012).

Evidence suggests that patients with low health literacy participate less in their health care. Low health literacy has been associated with less discussion about the feasibility of treatment plans (Schillinger et al., 2004), less desire to participate in health decision making (DeWalt et al., 2007), as well as providers assuming a paternalistic style of provider communication (Arthur, Geiser, Jacob Arriola, & Kripalani, 2009). Low literate patients ask overall fewer questions during medical encounters compared to those with higher health literacy; in addition, the types of questions are qualitatively different with low literate patients requesting repetition or clarification of information rather than seeking new knowledge (Katz et al., 2007). Low health literate parents of children also reported a strong preference for relying on the doctor's knowledge and leaving decisions up to the doctor (Yin et al., 2012). One study, however, found that diabetes patients with low health literacy, reported greater self-efficacy with care when the provider used a collaborative style, although this finding was not observed in patients with higher health literacy (Ishikawa & Yano, 2011). These findings suggest that patients with low health literacy depend and benefit from more direct interaction with the provider.

Measurement of Communication Processes

In an early meta-analysis, Roter, Hall, & Katz (1988) criticized the inconsistent theoretical and operational definitions of the communication process, identifying 247 descriptive variables in 61 studies. Accordingly, a number of

instruments have been developed to assess patient provider communication including analysis systems, scales, and direct interviews (Boon & Stewart, 1998; Roter et al., 1988).

Interactional Analysis Systems

Historically, communication researchers focused on the development of measures to quantitatively code the frequency of communication behaviors. Observation instruments relied on trained observers to ensure inter-rater reliability to analyze video or audio-taped interactions using Likert-rating scales, checklists of behaviors, or interactional analysis systems (Roter et al., 1988). These systems were linguistically based, focusing on the number and types of utterances observed by a third party coder (Street, 1992; Beckett et al., 2009). Because these measures focused on the quantity of communication events, they missed the quality of communication in the medical encounter and did not represent the patient's perspective (Epstein et al., 2005).

Communication Scales

Self-report scales draw on the perspective of patients, yielding scores that can easily be incorporated in statistical models (Epstein et al., 2005). Patient's perceptions of communication processes assessed by self-report surveys were better predictors of satisfaction with care than observer-coded measures (Street, 1992). In a study comparing parent reported and third party coder assessments of communication in 517 pediatric encounters, parents reported more

communication events than the coders (Beckett et al., 2009). This suggests that satisfaction with communication is related to perception more than actual events.

Interpersonal Processes of Care Survey

Responding to the fragmented definitions of communication, Stewart et al. (1999) proposed a comprehensive framework of Interpersonal Processes of Care in Vulnerable Populations (IPC) that included the domains of communication, decision-making, and interpersonal style between health care providers and patients. The framework was informed by a review of the communication literature, a review of existing instruments, as well as clinical experience with diverse racial/ethnic and socioeconomic groups; each domain presents clearly defined constructs (Stewart, Nápoles-Springer, Gregorich, & Santoyo-Olsson, 2007). The framework is operationally defined by 29 items in the IPC Survey. This study used 15 items from the communication and decision-making subscales to assess parents' perception of the quality of communication processes with diabetes educators (Stewart, et al., 1999).

Participant Interviews

Open ended or semi-structured interviews invite deeper exploration of phenomena (Plano- Clark & Creswell, 2011). For this study, parent interviews exploring communication with diabetes educators provided rich data from the parent perspective on clinical interactions (Epstein et al., 2005). Theoretical sampling of parents with low versus adequate health literacy allowed comparison

for the similarities and the differences between the two groups' description of communication processes (Glaser & Strauss, 1967).

Mixed Methods

Using a mixed methods design to collect and analyze both survey and interview data provided an opportunity for each data set to supplement the other as a means to verify and compare data on the same subject (Glaser & Strauss, 1967). Several studies examining the effects of health literacy on communication processes have used a mixed methods approach (Castro et al., 2007; Fang et al., 2009; Katz et al., 2007). For example, Fang et al. (2009), in their study of patients' understanding of the indications for Warfarin and the signs of stroke, merged data on the pervasive communication problems (quantitative data) with rich, illustrative descriptions from participants by level of health literacy (qualitative data). In another example, Katz et al. (2007) compared the number and types of questions asked by patients with different levels of health literacy finding that low literate patients asked fewer questions and different types of questions than patients with higher health literacy; the qualitative data on the type of questions (requests for repeat of information rather than seeking new information) provided richer data than a simple count of questions alone.

Although researchers more commonly expect congruent quantitative and qualitative results, the case of divergent findings deserves attention (Wagner et al., 2012). Because participants often assess provider communication favorably

(Beckett et al., 2009; Schillinger et al., 2004), parents may conceivably report more communication issues during a face-to-face interview than they report through a forced choice on a Likert scale in the survey assessment.

This chapter reviewed the social determinants of and the associated health outcomes of limited health literacy, establishing parents with limited health literacy as a vulnerable population as they seek diabetes care for their children. As well, research examining the link between limited health literacy and poor communication were reviewed. Data on the pervasiveness of communication problems for adults with limited health literacy was compelling. The effects of limited health literacy in pediatric specialty care remained unknown. Several health literacy and communication studies have used mixed methods. The findings from these studies showed the benefit of using mixed methods to provide rich, descriptive data. Extending upon prior adult research in health literacy and communication, this concurrent mixed methods study examined and explored how the process of communication between diabetes educators and parents in a pediatric diabetes clinic was affected by the level of parent health literacy.

Chapter 3

Methods and Procedures

This concurrent mixed methods study examined and explored how the level of parent health literacy affected the process of communication between diabetes educators and parents in a pediatric diabetes clinic. This chapter describes the rationale for a mixed methods design and the parent sample, setting, measurement methods, and procedures. Ethical considerations, data analysis, and delimitations are also discussed.

Research Design

The study used a mixed methods design to obtain richer data of parent health literacy and communication processes than could be gained by either quantitative or qualitative methods alone (Clark, 2010; Epstein et al., 2005). The quantitative aspect of the study relied on a deductive approach, using surveys and statistical techniques to test relationships between parent health literacy and parent reports of the quality of communication with diabetes educators (Clark, 2010). The qualitative aspect was inductive allowing me to pursue a deeper understanding of how communication was affected by the parents' level of health literacy (Clark, 2010). A mixed methods design gave the advantage of multiple points of view drawing on the strengths and compensating for the weaknesses of each method (Clark, 2010; Johnson & Onwuegbuzie, 2004).

Specifically, the study used a concurrent mixed methods design (Figure 1). Quantitative and qualitative data were collected at the same point in time, analyses of both data sets occurred separately, and mixing occurred in the interpretation phase. (Johnson, Onwuegbuzie, & Turner, 2007). The qualitative and quantitative data carried equal weight in this study (Creswell, Klassen, Plano Clark, & Smith, 2011).

Figure 3: Mixed Methods Study Design

Sample

Sampling Criteria

The sample frame included parents of children with type 1 diabetes followed at a large pediatric diabetes center in North Texas. For the quantitative aspect, a convenience sample of parents were recruited. For the qualitative aspect, a subset of parents were recruited to complete the semi-structured interviews; maximal variation sampling (Plano Clark & Creswell, 2011) was used to purposefully recruit parents with low health literacy ($REALM \leq 60$) and parents with adequate health literacy ($REALM > 60$). The intent was to learn from the perspectives of these two different groups of parents.

Inclusion criteria included parent of child with type 1 diabetes, English speaking (fluent or proficient to not require interpreter during clinic visits) and at least one visit with a diabetes educator in the last year. Exclusion criteria included parent of child with type 2 diabetes or parent with a cognitive or mental impairment that prevented them from participating in a survey or interview.

Sample Size Estimation

A power analysis using G*Power (Faul, Erdfelder, Buchner, & Lang, 2009) resulted in an estimated sample size of 162 parents for the quantitative aspect of the study. This estimation was based on a two tailed test, a moderate effect size $OR=2.5$, $\alpha = .05$, $\text{power} = .80$, and the probability of parent report of poor communication when the parent has low health literacy of 0.3. The effect size

was based on the moderate to large effect size differences found in a correlational study examining the quality of patient-provider communication in diabetic adults with low health literacy compared to those with high health literacy (Schillinger, Bindman, Wang, Stewart, & Piette, 2004). The probability of parent report of poor communication for the parent with low health literacy (0.3) was based on reports that 27-49% of patients with poor health literacy reported poor communication on the interpersonal processes of care subscales (Sudore, et al., 2009). The sample size for the qualitative aspect of the study was estimated as 20- 30 participants; recruitment continued until thematic saturation was realized (Creswell, 1998).

Setting

The Diabetes Center was located in a tertiary care pediatric facility in an urban area of North Texas serving urban, suburban and rural communities. The center saw a diverse patient population of approximately 1,600 children with type 1 diabetes. Eight diabetes educators (6 full-time and 2 part-time) saw all diabetes patients and their families for ½ hour appointments as part of the routine visit in the diabetes center. The educators reviewed the child's blood sugar logs, insulin doses, ketone doses, and discussed with the child and parents insulin dose adjustments and other recommendations for self-care.

Measurement Methods

Demographic Data

Demographic data were collected including the parent's age, race, household income, and highest level of education, English language spoken at home, parent diabetes status, and child's age, duration of diabetes, insulin regimen, metabolic control, and presence of co-morbidities and complications. Most data relied on parent self-report. The child's hemoglobin A1C levels from the year prior to day of data collection were retrieved from the medical record (Appendix B)

The Rapid Estimate of Adult Literacy in Medicine

Parent health literacy was assessed with The Rapid Estimate of Adult Literacy in Medicine (REALM), a word recognition and pronunciation test listing 66 health terms in increasing level of difficulty (Murphy, Davis, Long, Jackson, & Decker, 1993) (Appendix C). Participants were asked to read words in order, down the list, skipping words they did not know. REALM score was the total number of correctly pronounced words. The Cronbach's α was .96 in a diverse sample of adults (Shea et al., 2004) and has been used in parent samples (DeWalt, Dilling, Rosenthal, & Pignone, 2007). REALM has strong criterion validity with the Slosson Oral Reading Test-Revised (.96, $p < .0001$) and the Wide Range Achievement Test-Revised (.88, $p < .001$), both standardized tests for literacy. REALM scores ≤ 60 , equivalent to < 8 th grade reading level indicated

low health literacy (DeWalt et al., 2007; Shone, Conn, Sanders, & Halterman, 2009). REALM takes approximately 2-3 minutes to complete.

Interpersonal Processes of Care in Diverse Populations Survey

Parent-educator communication was measured using 15 items from 5 subscales of the Interpersonal Processes of Care in Diverse Populations Survey (IPC) (Appendix D). These IPC subscales measured multidimensional aspects of parent-provider communication including general clarity, explanations of diabetes condition, explanation of diabetes care, eliciting concerns, and decision-making. Positive IPC subscale scores have been associated with higher satisfaction with care (Wong, Korenbrot, & Stewart, 2004; Nápoles, et al., 2009), diabetes self-care (Piette, et al., 2003), mental and physical functioning (Aikens, et al., 2005), and health literacy (Schillinger et al., 2004), providing evidence of construct validity.

Participants reported the frequency of communication behaviors of diabetes educators over the past 12 months on a five-point Likert scale ranging from never to always. Higher scores indicated higher frequency of the communication behavior so in some cases, higher scores indicated better communication and in other cases, higher scores indicated worse communication. No items were reversed for scoring. Subscale scores were calculated by averaging items, with scores ranging from 1-5. (Stewart, 2007). The original Cronbach's α for the five subscales ranged from .70-.93 (Stewart et

al., 1999) and remained high in subsequent studies regardless of race, education level, glycemic control (Aikens et al., 2005) or health literacy level (Schillinger et al., 2004). The IPC subscales took approximately 5-10 minutes to complete.

Scores for the IPC subscales have been skewed towards positive relationships, violating the normality assumption for linear regression. The IPC subscale mean scores have been converted to a binary variable (good and poor quality of communication) to compute logistic regression (Piette et al., 2003; Schillinger et al., 2004). Although dichotomizing ordinal variables can result in a loss of measurement information with a concomitant loss in effect size (Cohen, 1983; MacCallum et al., 2002), the internal consistency of the IPC Survey remained intact after converting quality of communication into a binary variable ($\alpha = .91$) (Piette et al., 2003). Mean subscale scores of 1-3.5 for positive behaviors and score 3.5-5 for negative behaviors were categorized as poor quality of communication.

Semi-Structured Interviews

Semi-structured interviews were conducted for a more in depth study of parents' descriptions of communication with diabetes educators. Initial probes included:

Tell me about a time when you had to learn something you needed to know to take care of your child's diabetes. How did the educator communicate information so it was helpful? How about a time when it was not helpful?

There are words used in diabetes. What do these words mean to you? e.g. dose adjustment, insulin to carb ratio, ketones.

Interview, project, and coding memos were written at the time of interviews and during data analysis. Data analysis occurred concurrently to data collection allowing patterns emerging during initial interviews to inform subsequent interviews. The interviews took approximately 10-30 minutes to complete.

Procedure

Recruitment

Recruitment of parents occurred on the day of the child's clinic appointment. Eligible parents were identified in the clinic schedule and approached to explain the study's purpose and to obtain consent from parents who agreed to participate (Appendix E).

The PI set the stage for a genuine exchange with parents about their communication with diabetes educators. Introducing herself as a student researcher who was not affiliated with the Diabetes Center, the anonymity and confidentiality of responses were assured, emphasizing that study results would be presented as aggregate data and never as individual data. The PI also explained that parents' responses were not linked to a specific diabetes educator.

Survey and Interview

Parent surveys and interviews took place in a private clinic room. The PI completed the survey with all parent participants verbally, entering the data on Qualtrics to minimize missing data (online survey software). Qualtrics allowed survey data to be exported directly to SPSS avoiding a data entry process.

Interviews were conducted by the PI with a subset of parents. Interviews were recorded using a digital voice recorder, converted into a MP3 file, and transcribed verbatim. Memos were completed shortly after each interview and during data analysis. All parents completing the survey only or the survey and interview, received a \$10 gift card to Target as a thank you for their participation.

Ethical Considerations

Risk/Benefit Ratio

This study was approved by the Institutional Review Board at Cook Children's Hospital. The study carried minimal risk and potentially some benefits for parent participants. Limited health literacy has been associated with stigma (Paasche-Orlow & Wolf, 2008); half of adult patients with poor literacy reported feeling ashamed although 90% also reported that it would be helpful for their provider to know that they did not understand medical words (Wolf et al., 2007). To avoid stigmatizing parents, the study was framed within the larger context of communication between parents and diabetes educators. Because some parents

may have felt uncomfortable with survey items or interview questions, parents were offered the option to decline any question or to stop the study at any time.

Parents may have benefited directly from participation in the study by having the opportunity to discuss their child with diabetes and their interactions with diabetes educators. Some parents may have seen benefit from participating in a study that would inform training of diabetes educators.

Human Subjects Protection

Quantitative data: The demographic, REALM score, and IPC Survey were identified by subject code only and were entered directly into an online survey developed in Qualtrics. Qualtrics used Transport Layer Security encryption to protect data as it moved across the internet to the Qualtrics servers. Surveys on Qualtrics were stored in a password protected private account. All data was encrypted and stored on servers that were protected by high-end firewall systems and vulnerability scans were performed routinely. Data were downloaded to an SPSS database file and were stored in a password-protected file on a password-protected computer in a locked office in the Center for Nursing Research at the University of Texas at Arlington College of Nursing. Only the PI had access to these files.

Qualitative data: MP3 files and transcribed interviews, identified by subject code only, were stored in the private, password-protected folder on the PI's password-protected computer. Three years after the completion of the study the

transcribed interviews, MP3 files and any other electronic files will be deleted and consent forms will be crosscut shredded.

Quantitative Analysis

Statistical analyses of the quantitative data were conducted using Statistical Package for Social Sciences software, SPSS version 19.0 (SPSS Inc., 2009). Descriptive statistics were computed for parent's age, gender, race, educational level, income, English spoken at home, parent diabetes and the child's age, duration of diabetes, insulin regimen, and hemoglobin A1C level.

Prevalence of Low Health Literacy

The mean REALM score and standard deviation were computed. A REALM score ≤ 60 was used as the cut-off score for low health literacy, equivalent to a less than 8th grade reading level. The prevalence of low health literacy was calculated as the proportion of parents with REALM score ≤ 60 / total number of parents.

Association of Health Literacy and Communication

Quality of communication was the outcome variable. Mean scores for each communication subscale (general clarity, explanations of diabetes condition, explanation of diabetes care, eliciting concerns, and decision-making) were converted into a dichotomous variable, good (3.6-5) and poor

communication (≤ 3.5) for positive behaviors and good (< 3.5) and poor (3.5-5) for negative behaviors.

Continuous predictor variables included health literacy, years of education, income, duration of diabetes, and median hemoglobin A1C. Race was recoded into two dummy variables, Black and Hispanic, with White Non-Hispanic as the reference group. Purposeful selection of covariates using logistic regression was performed according to the recommendations of Hosmer and Lemeshow (2013). This process has been described for exploratory logistic regression and may be more appropriate than stepwise selection, backward elimination, and forward selection methods in a logistic regression model, especially in small samples (Bursac, et.al. 2008).

Purposeful selection began with an analysis of each variable as a single predictor of the outcome including health literacy (variable of interest) and other variables that have been associated with quality of communication including parent education level, income, race, and child's duration of diabetes, and hemoglobin A1C level (Howe, et al., 2012; Stevens, et al., 2005; Yin, et al., 2009). Predictors with p-values $\leq .25$, a significance level recommended by Hosmer and Lemeshow (2013) to identify important variables, were retained for multiple logistic regression analysis. Predictors that were not significant and were not confounders were removed. Predictors were considered confounders if the coefficient value of any remaining variables in the model changed by $> 20\%$. If a

change in coefficient values for any variable were greater than 20%, the removed variables must be added back into the model one by one (Hosmer & Lemeshow, 2013). Variables with p-values < .10, as recommended for exploratory logistic regression, were retained in the final main effects model.

A separate purposeful selection of covariates and logistic regression analysis was performed for each of the 5 IPC binary sub scores (good or poor-general clarity, explanation of diabetes condition, explanations of diabetes care, eliciting concerns, decision-making) to determine if health literacy or other covariates would be retained in the model. Odds ratios for each of the IPC binary sub scores were computed to examine each predictor's effect on quality of communication.

The Hosmer-Lemeshow goodness of fit test was computed to test the null hypothesis that there is no difference in between the observed and model predicted values. A Hosmer-Lemeshow statistic > .05, indicated that the model fit the data, failing to reject the null hypothesis (Hosmer & Lemeshow, 1997).

Qualitative Analysis

Interviews were audio-recorded and transcribed verbatim. Interview transcripts were uploaded to the qualitative software analysis program, NVIVO.10 to aid in data analysis (QSR International Pty Ltd, 2012). A directed content analysis approach was used to allow existing theory to guide a structured process for qualitative analysis (Hsieh and Shannon, 2005). The theoretical and

operational constructs of the Interpersonal Processes of Care (IPC) survey served as the initial coding scheme: General Clarity, Explanation of Condition, Explanation of Diabetes Care, Eliciting Concerns, and Decision Making. Each transcript was read and coded with these predetermined categories. After this initial deductive approach to coding, each IPC category was further explored allowing subcategories to emerge from the data. Subcategories were then merged, reduced, or eliminated to create succinct, non-redundant final subcategories. Although transcripts were initially read and coded without regard to the level of health literacy of the interview participant, matrix coding queries within NVIVO.10 allowed comparison of data for similarities and differences in perceptions of communication by parents with adequate health literacy versus those with low health literacy (Glaser & Strauss, 1967).

Qualitative analysis was performed simultaneously with data collection so that earlier findings informed later interviews, allowing me to pursue observations and patterns emerging in the data. Interviews continued until thematic saturation was attained. Analytic and code memos were used to track the development of patterns that emerged from the data. It was anticipated that the qualitative analysis may lend support to, extend upon, or contradict the findings from the quantitative data analyses of parents' perceptions of quality of communication.

Trustworthiness of the qualitative data was pursued with thematic saturation, triangulation, peer debriefing, and the maintenance of an audit trail

(Creswell & Miller, 2000). It is important to acknowledge the bias and assumptions of the researcher. As a pediatric advanced practice nurse and certified diabetes educator for 20+ years, I have taught many children and parents about type 1 diabetes in group classes and individual sessions. As well, I have been immersed in the health literacy and communication literature. With self-awareness of my biases and assumptions, I hoped to remain true to what parents told me as I analyzed and interpreted the data.

Mixed Methods Analysis

Data from the two data sets were merged and presented in side-by-side tables to facilitate interpretation of results (Creswell and Plano Clark, 2011). Particular attention was paid to the similarities and differences in experiences of parents with low health literacy compared to those with higher health literacy.

Delimitations

Although individuals who were non-English speaking were more likely to have poor health literacy (Sudore et al., 2009), including these parents would have added a substantial confounding variable. Including non-English speaking participants would require an interpreter, a larger sample size and more complex statistical analyses, both beyond the scope and feasibility for this study.

The study relied on parent report of communication processes with diabetes educators rather than direct observation or analysis of video or audio-recorded encounters. Although direct observation and parent report both have

their merit, this PI chose parent-report to explore parents' experiences with communication from their perspective rather than a pursuit of a linguistic analysis of encounters.

Summary

The purpose of this chapter was to discuss the methods and procedures for the study. First, mixed methods was presented as a strong design to analyze the multiple viewpoints of health literacy and communication processes. Second, the parent sample, setting, use of survey and interview measurement methods, and the procedures to conduct the study were described. Ethical considerations including an awareness of the potential stigma associated with health literacy studies were also discussed. Lastly, both quantitative and qualitative analyses and the delimitations of the study were described.

Chapter 4

Findings

The findings of this mixed methods study examining and exploring how parent health literacy affected communication with diabetes educators are presented in this chapter. Sample characteristics are presented first followed by the quantitative and qualitative data to answer the four research questions. The chapter concludes with a summary of additional findings.

Sample Characteristics

Of the 183 parents approached for study enrollment, 162 parents (89% participation) completed the survey. Participants were 81% mothers, 66% White, 73% with at least some college, and 50% with a household income greater than \$50,000/year. Approximately 10% of parents had either type 1 or type 2 diabetes themselves (Table 1).

The mean age of participants' children was 12.0 years (range 2-21 years, SD 3.8), with mean duration of diabetes of 4.2 years (range 1 month-16 years, SD 3.5), and mean hemoglobin A1C level of 9.2% (range 5.5-14.0, SD 1.7). All children were treated with basal/bolus insulin regimens delivered by injection or insulin pump. Parents reported thyroid disease in 16 children (9.9%) and celiac disease in 4 children (2.5%).

Table 1: Parent Characteristics

Characteristic	Number (%)
Mean age 40.4 years (SD 7.2)	
Parent	
Mother	132 (81.5%)
Father	30 (18.5%)
Race/Ethnicity	
White	107 (66%)
Black	31 (19%)
Hispanic	24 (15%)
Education	
Some high school or less	8 (5%)
High school graduate or GED	35 (22%)
College graduate or some college	109 (67%)
Graduate degree	10 (5%)
Income	
Under \$15,000	18 (11%)
\$15,000-24,999	16 (10%)
\$25,000-34,999	14 (8.6%)
\$35,000-49,999	34 (21%)
\$50,000-74,999	27 (16.7%)
\$75,000-99,999	17 (10.5%)
\$100,000 and over	34 (21%)
English spoken at home	158 (97%)
Parent with diabetes	
Type 1 diabetes	9 (5.5%)
Type 2 diabetes	7 (4.3%)

Research Aim 1: Prevalence of Low Health Literacy

Research aim 1 was to determine the prevalence of low health literacy in a sample of parents of children with type 1 diabetes in North Texas. REALM scores ranged from 4-66 with a mean REALM score of 62.8 (SD 6.7). Defining

low health literacy as a REALM score ≤ 60 , 18.5% of parents were assessed with low health literacy.

Research Aim 2: Health Literacy and Communication

Research Aim 2 was to determine the relationship between parent health literacy and quality of communication. Mean scores for each Interpersonal Processes of Care (IPC) subscale were converted into a binary variable, good and poor communication. Perceptions of poor communication ranged from 6-38% across the five IPC subscales with a greater percentage of parents with adequate health literacy reporting poor communication for all subscales except General Clarity (Table 2). Cronbach's alpha values of the subscales were acceptable, ranging from .57 - .80.

Figure 4: Percent of Parents Reporting Poor Communication

Logistic regression analysis with each of the 5 converted, binary IPC subscores (good or poor communication) as the dependent variable and REALM (health literacy), race, income, education, duration of diabetes, and hemoglobin A1C level as the predictor variables were performed. Tests of multicollinearity indicated a very low level of multicollinearity with an acceptable variable inflation factor < 1.7 for each predictor (Peng, et al., 2002). Using the method of purposeful selection described by Hosmer and Lemeshow (2013), significant predictors with $p \leq .10$ were retained in the final models (Table 2).

Table 2: Logistic Regression Predicting Poor Communication

IPC Subscale	Predictor	OR	p
General Clarity	Health literacy	.945	.05
Explain Condition			
Explain Care	Duration diabetes	1.15	.05
Elicit Concerns			
Decision-Making	Years education	1.186	.083
	Duration diabetes	1.118	.027
	Black race	.391	.086

General clarity

The final logistic regression model after testing covariates and confounders yielded one significant predictor, REALM for general clarity. The odds ratio for REALM score was .953 ($p=.05$), indicating that every one-point

increase in REALM score was associated with a 5.5% decrease in odds of reporting poor communication for general clarity. The Hosmer-Lemeshow goodness of fit test was non-significant ($\chi^2 (3) = .764, p = .858$) indicating that the model fit the data.

Explanations of diabetes care

The final logistic regression model for explanations of diabetes care included one significant predictor, duration of diabetes. The odds ratio for duration of diabetes was 1.15 ($p = .05$), indicating that for every 1 year increase in duration of diabetes diagnosis, parents were 15% more likely to report poor communication for explanations of diabetes care. The Hosmer-Lemeshow goodness of fit statistic was non-significant $\chi^2 (2) = .4.755, p = .783$ indicating that the model fit the data.

Decision making

The final logistic regression model for the decision-making subscales included three significant predictors, years of education, duration of diabetes, and Black race. The odds ratio for years of education was 1.186 ($p = .083$), indicating that for every 1 year increase in education, parents were 19% more likely to report poor communication on the decision-making subscale. The odds ratio for duration of diabetes was 1.118 ($p = .027$), indicating that for every 1 year increase in duration of diabetes diagnosis, parents were 12% more likely to report poor communication for decision-making. The odds ratio for Black race was .391

($p=.086$) indicating that Black parents were 61% less likely to report poor communication for decision-making than White parents. The Hosmer-Lemeshow goodness of fit statistic was non-significant $\chi^2 (8) = 9.673$, $p=.289$ indicating that the model fit the data.

Research Aim 3: Parent Experiences of Communication

Research aim 3 was to describe parents' experiences of face-to-face communication with diabetes educators with attention to differences by health literacy level. A subsample of 24 parents, 13 with adequate and 11 with low health literacy, participated in semi structured interviews. The sample included 71% mothers, 50% White, 63% with at least some college education, and 46% with income greater than \$50,000/year. The duration of diabetes for their children ranged from 1 month to 16 years, with a mean of 4.1 years. (Table 3). Length of parent interviews ranged from 6 to 38 minutes, and averaged 16 minutes. The interviews were concluded when parents had no more information to add or when the interview was interrupted by the start of their clinic appointment.

Table 3: Characteristics of interview participants

Parent	Health Literacy	Parent	Race/Ethnicity	Education	Income	Duration Diabetes
1	Adequate	Father	White	Some college	>100K	3 years
2	Adequate	Mother	White	College grad	75-99K	3 months
3	Adequate	Mother	White	Some college	35-50K	2 years
4	Adequate	Mother	White	H.S. grad	35-50K	3 years
5	Adequate	Father	White	H.S. grad	>100K	1 year
6	Adequate	Father	White	Some college	>100K	1 year
7	Low	Mother	Black	Some college	15-25K	16 years
8	Adequate	Mother	White	College grad	35-50K	1 year
9	Low	Father	Black	H.S. grad	15-25K	1 year

Table 3 - *Continued*

10	Low	Mother	White	College grad	>100K	2 years
11	Low	Mother	Black	Some college	35-50K	6 years
12	Low	Mother	Hispanic	H.S. grad	25-35K	1 month
13	Adequate	Mother	White	Grad School	>100K	8 years
14	Adequate	Mother	Black	College grad	35-50K	4 years
15	Adequate	Mother	White	College grad	>100K	5 years
16	Adequate	Mother	White	H.S. grad	50-75K	5 years
17	Low	Father	Black	Some college	50-75K	8 years
18	Low	Mother	Hispanic	Less than H.S.	<15K	6 years
19	Adequate	Father	White	College grad	50-75K	4 years
20	Low	Mother	Black	Some college	<15K	10 years
21	Low	Father	Black	H.S. grad	35-50K	5 years
22	Adequate	Mother	Black	Some college	35-50K	1 year
23	Low	Mother	Black	H.S. grad	15-25K	4 years
24	Low	Mother	White	Some college	75-99K	4 years

Directed content analysis of the interview data provided an in depth perspective on parents' perceptions of communication with diabetes educators (Hsieh and Shannon, 2005). To focus on the communication processes measured in the quantitative aspect of the study, the constructs of the Interpersonal Processes of Care Survey provided the basis for initial coding and data reduction (general clarity, explanations of diabetes, explanations of diabetes care, eliciting concerns, and decision making). Each of these categories were further analyzed, allowing subcategories to emerge inductively. Subcategories were not static, as a new subcategory emerged, previously read transcripts were re-read to determine if the subcategory held across interviews.

Sixteen original subcategories were reduced or eliminated (unrelated to communication) into 8 subcategories. Using the matrix coding function in

NVIVO.10, data representing each subcategory were sorted by level of health literacy. This allowed comparison of the similarities and differences in the experiences of communication with diabetes educators for parents with adequate health literacy and those with low health literacy. Figure 4 depicts the subcategories describing the communication process; subcategories that revealed differences by health literacy level are italicized and bolded.

Figure 5: Emerging Subcategories in Conceptual Framework

Parent experiences with general clarity

General clarity referred to the ability of diabetes educators to use vocabulary familiar to the parent and to speak clearly and slowly. All parents reported some confusion with words commonly used in diabetes care, including honeymoon period, peaks of insulin, carbohydrate ratios, hemoglobin A1C, average blood sugar, and free foods. Parents with low health literacy frequently made statements during the interviews that suggested confusion with diabetes words. For instance, one parent spoke of insulin dosing, “If it’s a certain high, I give him so many ounces, if it’s low, I give so many ounces.” (correct word, units). Although most parents could describe the ratios they used to calculate insulin doses e.g. 1 to 10 and 1 to 50, some parents could not apply the correct label or arbitrarily interchanged the labels of insulin to carbohydrate ratio and correction factor. One parent showed a lack of understanding of the term “sliding scale,” a commonly used written tool to determine insulin doses:

“I knew that it’s called a sliding scale but I’ve been doing it in the machine.” (confusing sliding scale with glucose monitor)

Additionally, low literate parents revealed their misinterpretation of common diabetes information. For example, diabetes educators typically explain that type 1 diabetes is a result of an autoimmune process in which the islet cells of the pancreas are attacked and destroyed. One parent’s misinterpretation of this common explanation:

“I know like one of the soldiers, he goes to Afghanistan and they attacked the pancreas so it doesn’t work.”

Misinterpreted instructions left parents in doubt about diabetes care. One parent in her recall of explanations given to her about “peaks of insulin” was unable to describe “peaks” in pharmacological terms, remaining unsure if this meant that she should check her child’s blood sugar (correct) or re-dose her child’s insulin (incorrect).

For parents with adequate health literacy, their initial confusion with terms was easily corrected through discussions with the diabetes educators.

“I knew what A1C meant, average blood sugar over a period of time. But I didn’t understand how they came up with this out of a single blood work. I initially thought, they just log it and then they take all his blood sugars and average it out... I inquired her [diabetes educator] about it, I was misunderstanding how you came up with this, how do you do this, and she told me.”

Parent experiences with explanations of diabetes

Many parents recalled the three day *Crash Course* during the initial hospitalization when their child was diagnosed with type 1 diabetes. The experience was similar regardless of health literacy level. Parents recalled receiving a tremendous amount of information that was both helpful and overwhelming. All parents described being upset, in shock, scared, sad, and overwhelmed at the time of diagnosis. Some parents recalled being unable to hear and learn the diabetes information, needing time to take in the diagnosis.

For a few parents, they recalled becoming defensive and hostile towards the educators which impeded or delayed communication.

Parent experiences with explanations of diabetes care

Explanation of diabetes care referred to diabetes information provided to parents about how to care for their child at home, including glucose monitoring, insulin dosing, and sick day management. From an analysis of the *Explanation of Diabetes Care* category, three subcategories emerged: *teach us what to do vs. how to think*, *teach us at our pace*, and *how we learn*. Parents with low health literacy and adequate health literacy offered different perspectives on these aspects of communication.

Teach us what to do vs. how to think described the differences in learning needs between parents with low health literacy compared to parents with adequate health literacy. Parents with low health literacy focused on learning diabetes tasks or the basic safety skills of diabetes management. They wanted instructions on how to recognize and treat lows, to draw up insulin doses, and to make a daily schedule. They depended on interactions with the diabetes educators to tell them what to do and to keep them accountable, “They tell me exactly what I have to do.”

In contrast, health literate parents described communicating with diabetes educators about glucose trends, dose adjustment, and how exercise, stress, and carbohydrates influenced blood sugar control. They wanted to learn how the

diabetes educator considered and interpreted these factors that influenced blood sugars to make diabetes management decisions.

“I always asked questions to make sure I understood why they were making a certain adjustment [insulin], why they were making a change so that when it came time for me to have to do it, I would know how.”

Parents with adequate health literacy wanted clear expectations about their role in diabetes management. Although some parents reported explicit communication about moving towards independent management, others were unclear.

“I didn’t know we were working towards working on our own by ourselves, I thought that it (insulin regimen) was like a prescription, you don’t mess with that.”

Diabetes educators were viewed as a resource to help parents become independent with their child’s diabetes care. In their interactions, parents saw themselves as the manager of their child’s diabetes, expecting to have discussions rather than mandates of treatment options.

“The people here are one resource for us but they seem to be managing like it’s their process. That’s where the conflict is really. They’re a resource, and it’s not a situation where they’re remotely managing the situation.”

Teach us at our pace referred to how diabetes information was provided in terms of the breadth of content and the rate at which it was delivered. Parents with low health literacy reported the need for patience, to not be rushed, and to have information repeated.

“I have to be repeatedly told things...maybe not to rush things too much. I understand that the educators, that they do it on a daily basis and they're probably used to going through it, just to maybe not rush.”

As well, they spoke about the need for information to be broken down to their level so they would know what to do.

“Learning, don't overwhelm a parent... just the main things, check, correction, ketones. They give us so much it's hard ... so I think that we need to break it down to what's the most important thing.”

Parents with adequate health literacy provided a very different perspective on the pace of diabetes communication. They frequently spoke about their frustration with communication about diabetes information that seemed to “address the least common denominator.”

“They had to make sure that everyone who comes in had to understand the very basic level. Which is fine, certainly you'd do that, but I think you have to be flexible enough to move at their pace- whoever that is. And I think we were ready to move at a little quicker pace than what they were.”

Some even felt held back from learning:

“Early on in the process, they gave us very limited information. Almost like spoon feeding you things and saying that certain points you're not ready to know which is very frustrating, because we want to know up front everything.”

As well, parents perceived that the limited information affected how they cared for their child's diabetes. “At each visit you learned something, but it's not the whole picture.” Without a broader understanding of diabetes and glucose

management, parents tried to interpret the effects of their diabetes decisions based on their limited knowledge.

We know the carbs, we know our ratio, the expected results is not there, because there are a lot of other things we know now that could affect the outcome and affect his blood sugar level. So, those are things that early on, that they didn't really discuss very much.

How We Learn referred to parents' descriptions of both helpful and unhelpful ways to communicate diabetes information. The majority of parents with low health literacy reported that verbal discussion of diabetes information was not adequate, "if you just tell me, I might not remember." Similarly, parents did not rely on written information provided to them, "if you've given me a book, I'm not going to do nothing with that book, I'm just going to put it to the side."

Instead, they suggested that communication of diabetes information would be more helpful if the diabetes educators used visual diagrams, hands on demonstration, and practice simulations. Parents reported that the use of food models was very helpful, giving them the opportunity to put meals together, to count carbohydrates, and to dose insulin. Extending on their experience with learning carbohydrate counting, low literate parents suggested more hands-on instruction "if you're talking about ketones, pull out a ketone strip."

Like parents with low health literacy, some health literate parents reported that hands-on demonstration would be helpful. However, more parents relied on a dialogue with the diabetes educator to learn diabetes care. They suggested

verbal scenarios presented as a series of 'what if questions' would be helpful to learn decision making in diabetes management.

"The way I would approach it is talk through what they're thinking, here's the thought process. What do you think about these numbers, what do you think about these doses? And kind of push someone into that arena of making those decisions."

Parents with adequate health literacy were actively thinking through decisions, for themselves, on how to manage their child's diabetes. When they did not understand an educator's recommendation, they pursued the educator for explanations.

"There was a time I thought he needed his dinner adjusted but it was his Lantus that needed to be adjusted and I got very concerned because I didn't understand why. I actually ended up talking to the educator saying, hey, can you please explain to me why we made the Lantus change instead of a dinner change?"

Parents did not want to be told what to do but preferred to be guided in how to think about what to do.

"Sit down with us and ask how is the patient is doing, and basically backwards. Don't say you need to do this because this is happening. Say okay, what do you think about this? Okay, that's a good thought or I see why you think that, but could you try this approach?"

Parent experiences with eliciting concerns

This category described the educator's ability to elicit and discuss the most important concerns and to listen carefully without being distracted. Parents with low health literacy asked questions to clarify diabetes information, expecting diabetes educators to help them with immediate concerns related to basic

diabetes care. For example, parents described the help they needed for sick day management, depending on the educators to ‘walk me through step by step’.

In contrast, parents with adequate health literacy asked questions to elicit new information. They described being proactive in their communication with the diabetes educators, bringing lists of questions to discuss during clinic visits. They hoped to drive the *pace* of diabetes information provided to them.

“ There’s a specific reason we asked that question. It’s not just to ask...in real life this has come to us, and so this is what we need to deal with it. Things don’t come up in real life in a convenient order.”

Sometimes their efforts were frustrated when the diabetes educator failed to address and dismissed their concern.

“ It almost felt like they try to intentionally keep things from us. Because they would tell us, well you’ll learn that later. We ask specific questions, oh, you’ll learn that later...and we’re not like that, we want to know now, to prepare ourselves.”

Parents spoke about the need for time to promote communication between the provider and parent. Given the real time constraints of a busy clinic, parents described the diabetes educator and the parent participating in routine interactions to efficiently complete a clinic visit.

“It is more routine questioning and routine answers...We fill out a form every time, and they go over it, are there any changes, do you have any questions?”

They suggested that a diabetes educator could ask about concerns in a more forthright manner, leading to a more sincere exchange.

... now that we've went all over this, do you really understand what is going on? Do you foresee having any problems or is there just one thing that's just really bothering you or that you're not clear of? That's like to me a genuine concern, saying, hey, I get that I may have patients waiting, but I'm dealing with you right now."

In addition, parents felt that communication relied on a true exchange of information with both the diabetes educator and the parent having important information to share.

" It's kinda like a Catch 22. You don't know what I know and I don't know what you know. But, in the communication breakdown, well how do we get that information to each other. How do I tell you what I know? How do you know? "

Parent experiences with decision making

Decision making described how the educator determined the extent to which parents could and wanted to fulfill expectations of the diabetes regimen, asking if the parents anticipated any problems doing the recommended regimen, and understanding and modifying the regimen accordingly. In the analysis of the *decision making* category, two subcategories that were similar across health literacy levels emerged, *walk in my shoes* and *the educator's tone*.

Walk in my shoes referred to parents' belief that diabetes educators did not always understand the stressors in their daily life that affected diabetes care for their child. "There's all these stressors that they don't realize are happening behind closed doors." Parents spoke about financial constraints, struggles with insurance companies, and the juggling of work and home. Many did not share their worries with the diabetes educators because of lack of time or a consistent

relationship, or because of their own embarrassment. Parents appreciated that diabetes educators worked hard to communicate diabetes information but felt that it would be more helpful if diabetes educators could “walk in my shoes,” empathizing with the realities of their life with diabetes.

The educator’s tone described how diabetes educators, through their tone of voice, were either encouraging or discouraging for parents. Parents wanted the educator to have patience, and to give encouragement and reassurance during every interaction.

“ They need to be very encouraging, I mean not really talk down to us like we’re stupid...Even though the question might sound stupid cause the educators have answered it 500 times that day, it’s not stupid to that parent or they wouldn’t be asking it.”

They wanted comfort from the diabetes educators that “everything is going to be okay” and that they were “doing a good job, doing the right thing, and making good decisions.”

“Encourage us and make us feel like we are doing a good job and that you know we’re trying. I can get very discouraged quickly if I don’t feel like I’m doing something right so encouragement is really crucial for us parents.”

Parents perceived interactions as discouraging when the diabetes educator was impatient, or they felt “talked down to” or “scolded.” Parents reported negative interactions when they failed to bring blood sugar logs to clinic, disagreed on the responsibilities of diabetes care between themselves and their child, or when their child had poor diabetes control. Some parents became very

discouraged, becoming hostile and opting out of further communication about the child's diabetes care.

There's a level of disrespect with the parents that comes to a point where I feel like I've been constantly talked down to. And that makes me want to shut down as a parent and not listen to you.

Everybody has to be patient. They have a person there so eager, and you can destroy them. Because that person was in a position to really usher me on, to be an encouragement. So I can be better. But I just said no, forget it.

Research Aim 4: Integration of Quantitative/Qualitative Data

Quantitative and qualitative data were integrated for a final analysis and interpretation. Both multivariate and content analyses found that parents with low health literacy reported poorer understanding of diabetes jargon. Although multivariate analysis did not find a relationship between health literacy and the explanations of diabetes care or the eliciting concerns subscales, the qualitative data revealed differences for parents with low and adequate health literacy. No differences across health literacy levels were found for communication related to explanations of condition and decision making (Table 4).

Table 4: Integrated Quantitative and Qualitative Results

Quantitative Results			Qualitative Results		
IPC Subscale/ Category	OR	p-value	Sub-Categories	Summary Parents with Low Health Literacy	Summary Parents with Adequate Health Literacy
General Clarity	.945	.05	General Clarity	Confused with diabetes jargon; Misunderstood and misused words	Initially confused with diabetes jargon; understood when clarified
Explain condition	1.017	.816	Crash course	3 day hospital admission for intensive diabetes education	
Explain Diabetes Care	1.321	.15	Teach us what to do vs. how to think	Focused on tasks	Focused on problem-solving
			Teach us at our pace	Break it down, repeat, and do not rush	Provide comprehensive information when wanted
			How we learn	Written/verbal information not adequate. Visuals, hands on demonstration, practice simulation would be helpful.	Some hands-on demonstration and practice, and verbal dialogue to encourage problem solving would be helpful.
Eliciting concerns	.996	.929	Eliciting concerns	Questions focused on clarifying information	Questions focused on obtaining new information
Decision-Making	1.015	.681	Walk in our shoes	Wish for diabetes educators to know and consider other life stressors, to see diabetes management in a greater life context.	
			The educator's tone	Manner of educator is perceived as encouraging or discouraging for parents.	

Additional Findings

Parents, irrespective of health literacy level, spoke about the difficulties of parenting a child with type 1 diabetes, especially teens; they reported a need for information about effective parenting skills and goal-oriented discussions about transition of their child to independent self-care. They also spoke about their fears, including fear of needles, of hypoglycemic reactions, and of long-term complications.

Measures for Achieving Trustworthiness of Data

Interviews proceeded until thematic saturation was realized. Analytic and code memos were kept throughout the research process, creating an audit trail. The Director of Nursing Research at Cook Children's Hospital, a doctorally prepared nurse and expert in qualitative methods, provided ongoing peer debriefing; this involved a review of the study design, reading of transcripts, and discussions of the emerging and final categories and subcategories. Retrospective debriefing was completed with two experts in pediatric diabetes.

Summary

The quantitative and qualitative findings of this mixed methods study were presented to answer the four research questions. The chapter concluded with a report of additional findings.

Chapter 5

Discussion

This concurrent mixed methods study examined and explored how the level of parent health literacy affected the process of communication between parents and diabetes educators in a pediatric diabetes clinic. Two research hypotheses were proposed apriori: (1) parents with low health literacy would be more likely to report poorer communication processes than parents with higher health literacy; (2) parents with low health literacy would report different experiences of communication with diabetes educators than parents with adequate health literacy. Although the quantitative data alone did not fully support the first hypothesis, the quantitative and qualitative data together suggest that parent health literacy does affect parents' communication with diabetes educators; parents with low and adequate health literacy reported different perceptions of the communication process.

This chapter presents the interpretations of the major quantitative and qualitative findings, and the limitations, conclusion, and clinical implications of this study. The chapter concludes with recommendations for additional research.

Interpretation of Major Findings

Prevalence of Low Health Literacy

In this study, 18.5% of parents were assessed as having low health literacy, similar to the estimate of 17% reported for a previous sample of parents of children with type 1 diabetes (Hassan & Heptulla, 2010). Although the 18.5%

prevalence rate of low health literacy for the parents in this study falls within the rates of 1-29% reported for a variety of parent samples (DeWalt, Dilling, Rosenthal, & Pignone, 2007; Driessnack, Chung, Perkhounkova, & Hein, 2013; Kumar et al., 2010; Otal et al., 2012; Wittich, Mangan, Grad, Wang, & Gerald, 2007; Yin et al., 2009), it is lower than the 28.7% prevalence rate reported for a national sample of parents (Yin et al., 2009). Although no longitudinal data have been reported examining the change in health literacy level after the diagnosis of diabetes, it is plausible that parents, experienced in the health care demands of caring for a child with type 1 diabetes, may have improved health literacy.

Health Literacy and Communication

Prior studies have found that more low health literate patients compared to health literate patients reported poor communication on the same Interpersonal Processes of Care (IPC) subscales used in this study; these same studies reported strong associations between health literacy and IPC communication outcomes (Schillinger, et al., 2004; Sudore, et al., 2009). Surprisingly, in this study, more parents with adequate health literacy than those with low health literacy reported poor IPC communication outcomes. Additionally, this study did not find significant associations between health literacy and 4 out of the 5 IPC communication outcomes; health literacy was positively associated with the IPC general clarity outcome only.

There are several possible explanations for these unexpected outcomes. First, this is one of the first times that the Interpersonal Processes of Care Survey

has been used in a sample of parents caring for their children. The sample of parents in this study was less diverse, more affluent, and more educated than previous adult samples reporting IPC survey data. Participants in this study were primarily White, educated, affluent, English speaking mothers of children with type 1 diabetes. The differences in socio-demographic characteristics between this study's sample and previous samples may explain the disparate communication outcomes.

Second, parents' view of themselves and their expectations of the clinic interaction may have affected their reports on communication with diabetes educators. Parents with adequate health literacy maintained high expectations of the diabetes educators, which possibly explains their more frequent reports of poor communication. This finding is consistent with those of Jensen, King, Guntzviller, & Davis (2009) who found that literate patients were more critical of communication with their health care provider as a result of being active and assertive during clinical interactions. In contrast, low literate parents may experience shame and stigma during clinic interactions (Paasche-Orlow & Wolf, 2008), assuming that communication problems are a result of their illiteracy rather than poor communication behaviors of the diabetes educator. Similar to other vulnerable population groups, low literate parents may be more subject to social desirability bias. They may be reluctant to answer unfavorably when asked about communication with diabetes educators.

Third, this study examined the communication processes between parents and diabetes educators. Previous studies have focused on physician communication behaviors (Fang et al., 2009; Schillinger, et al., 2004; Sudore, et al., 2009). Diabetes educators, with specially trained skills in diabetes education, may be more attuned to the needs of parents with low health literacy. As well, the educators typically spent a tremendous amount of time with these parents during the initial three-day admission and at appointments every three months. As a result, parents with low health literacy may perceive fewer problems with the communication process than adult patients who relied on the physician to communicate diabetes information during brief, routine outpatient visits.

The effect of health literacy on perceptions of communication in this parent sample appears to be small. Presumably, other variables not considered in this study may be influencing the perception of the communication process. Although this study focused on the information-giving aspects of communication, relational aspects may be influencing parents' perception of the communication process.

Interpretation of Quantitative and Qualitative Data

Interpretations of the quantitative and qualitative data together provide insight into how parent health literacy affected parents' perceptions of communication with diabetes educators. The quantitative and qualitative data were convergent across some of the subscales/categories, while for others they were divergent. Rather than perceiving communication processes as better or

poorer, parents with low health literacy and parents with adequate health literacy reported different communication needs.

Health literacy and lack of general clarity

Both statistical and content analyses of the data suggest that parents with low health literacy were more likely to be confused with diabetes jargon. Many studies have reported patients' misunderstanding of medical terms; words commonly used as everyday language for health professionals may not be known by the general population (Fang et al., 2009; Jordan, Buchbinder, & Osborne, 2010; Sakraida & Robinson, 2009). Adult diabetes patients with low health literacy were much more likely to report that their doctor used words that they did not understand (Schillinger, et al., 2004).

Parents with low health literacy revealed their confusion by misusing or misinterpreting common diabetes words during the course of the interviews. Parents' use of diabetes jargon, although incorrectly, showed their attempt to communicate within the medical culture of diabetes. Previous findings have shown that parents believed they needed to use medical terms to participate in their child's care (Pizur-Barnekow, Darragh, & Johnston, 2011). In this study, parents' interpretation of diabetes jargon seemed borrowed from laymen concepts, adapting medical terms from their knowledge of words familiar to them: a sliding scale was a machine, an ounce of insulin was a recognizable unit of measurement, and an attack on islet cells was done by soldiers. Castro, et al.

(2007) also found that patients misused words, substituting familiar words for medical terms, for example, daily for dialysis.

Health literacy and explanation of condition

No association between health literacy and explanation of condition was found. Similarly, the interview data revealed that parents, regardless of health literacy, spoke about the *Crash Course*, a 3-day hospital admission at the time of diagnosis that focused intensively on diabetes education. All agreed that the diabetes education was comprehensive, covering 'survival skills' (Silverstein et al., 2005). These findings contradict previous findings. Adult diabetes patients with low health literacy were much more likely to report that they did not understand explanations of their condition (Sudore, et al., 2009; Schillinger et al., 2004). In these adult studies, patients received diabetes education from the primary care doctor in an outpatient setting. In comparison, diabetes educators spent extensive time with parents both in the *Crash Course* at the time of diagnosis and in ongoing, regularly scheduled outpatient appointments. These differences in health care delivery for pediatric versus adult patients with diabetes may explain the contradictory findings.

Health literacy and explanations of diabetes care

Although statistical analysis found no association between health literacy and explanations of diabetes care, the qualitative data revealed distinct differences for parents with low compared to those with adequate health literacy.

Parents with low health literacy. Low health literate parents depended on the diabetes educators to tell them what to do for diabetes care, focusing on the tasks or survival skills of diabetes care. This finding is consistent with previous findings that have found that low literate patients were more passive, relying on the health care provider to make decisions and to dictate care (Arthur, et al., 2009; Yin, et al., 2012).

Parents with low health literacy recommended that diabetes educators communicate diabetes information at a slow pace by breaking it down to the key points and repeating the information often. Prior studies have also found that patients, including those with low health literacy, appreciated medical information that was broken down for them into understandable terms (Bennett, Switzer, Aguirre, Evans, & Barg, 2006; Pizure-Banekow, et. Al, 2011). Although parents recognized that communicating diabetes content was routine for the diabetes educators, they spoke extensively about not being rushed through the diabetes education in order to have the time to process and retain information (Jordan et al., 2010).

In this study, verbal communication of information alone was not adequate but would be more readily received if visual displays, hands on demonstration, and practice simulations were also incorporated into diabetes teaching. Previous studies have found that diabetes education is often delivered using didactic methods (Ellis et al., 2004) despite being less effective than more interactive strategies (Swift, 2009). Demonstration has been shown to be most effective in

improving knowledge and patient outcomes (Friedman, Cosby, Boyko, Hatton-Bauer, & Turnbull, 2011).

Parents with adequate literacy. Parents with adequate health literacy reported more problems with communication of diabetes information. This was an unanticipated finding as previous studies have reported better communication processes for patients with adequate health literacy (Fang et al., 2009; Schillinger et al., 2004; Sudore, et al., 2009). Furthermore, this is one of few studies to report qualitative data on the communication processes for persons with adequate health literacy.

Health literate parents considered themselves as the manager of their children's diabetes, viewing the diabetes educator as a resource. They asked questions to push for information that was most relevant to them. These findings are consistent with prior studies that found that patients developed self-advocacy skills to obtain, clarify, and to make informed decisions about health care (Jordan et al., 2010; Sakraida & Robinson, 2009). In a qualitative study with parents of children with special needs, assertive communication was a theme describing how parents learned to be persistent with questions, demanding information they wanted but had not been provided by the clinician (Pizur-Barnekow et al., 2011).

Although some parents with adequate health literacy felt that hands-on experience would be helpful to learn diabetes care, more parents wanted an ongoing dialogue with diabetes educators. They hoped that the educator would walk them through a series of questions to promote the problem-solving skills

needed to interpret and act upon the interrelated factors of carbohydrate intake, activity, and insulin dosing that affect blood glucose levels (Swift, 2009). Parents described a process that resembled Socratic questioning, a teaching strategy in which probing, clarifying questions are used to deepen knowledge and to teach parents how to think for themselves (Billings & Halstead, 2012).

Health literacy and eliciting concerns

Although statistical analysis found no association between health literacy and communication related to eliciting concerns, the qualitative data illustrated differences for parents with low versus adequate health literacy. Parents with low health literacy asked questions to clarify information on what to do to manage their child's diabetes. In contrast, parents with adequate health literacy asked questions to gain new knowledge pushing the *pace* of diabetes education. This finding confirms prior research describing the qualitatively different types of questions asked by low and adequate health literate patients (Katz, et al., 2007).

In addition, parents with adequate health literacy reported frustration with the lack of flexibility to discuss diabetes topics applicable for them at any given time. Rather than experiencing their child's diabetes as discrete topics, their understanding of diabetes was more holistic and dynamic in nature; their questions about diabetes care did not follow a sequential pattern but instead arose in response to life circumstances.

Health literacy and decision-making

Although the focus of this study was on the information-giving aspects of communication between diabetes educators and parents, it must be noted that parents discussed extensively the relational aspects of communication. When asked if the diabetes educators asked whether they would have any problems doing the prescribed diabetes regimen, parents did not discuss miscommunication or misunderstanding of diabetes information. Instead, parents brought up the need for diabetes educators to understand that they took care of their children's diabetes within a larger context of life circumstances. As well, they spoke about the need for encouragement and affirmation of the care they gave their child. Parents in this study did not separate the information-giving from the relational aspects of communication, confirming the need for clinicians to attend to their affective stance when communicating diabetes information (Howe, et al., 2012).

Limitations

This study has several limitations. A convenience sample of parents was recruited for this study. Parents who did not attend clinic visits regularly with their children may be different (e.g. health literacy) than responders. Since parents were recruited from a diabetes specialty care practice, results from this study cannot be generalized to other practice settings. Future replication studies with new samples in different settings would increase the generalizability of this study's findings.

The sample size may have been insufficient. Previous studies examining associations between health literacy and communication have found moderate-to-large effect size differences in the quality of communication for patients with low and those with adequate health literacy (Schillinger, et al., 2004; Sudore, et al., 2009). The effect of health literacy on the IPC communication outcomes in this parent sample may be much smaller than in previous samples. As a result, this study may have been underpowered to detect an association between health literacy and the IPC communication outcome variables.

Another limitation is that most data were obtained by parent self-report. Parents' report of sociodemographic information relied on their memory and accuracy of reporting and was subject to recall bias. As well, parents' self-report on the Interpersonal Processes of Care Survey items were of concern. Poor communication may have been overestimated in some cases because parents may have rated items negatively when they were not relevant to their current needs. For example, one item asks how often the diabetes educator reviews all of your child's insulin and medications. Although this may be a critical question for adult patients on multiple medications, parents did not find this a concern. Conversely, poor communication may have been underestimated because of social desirability bias, making it more likely for parents to answer positively about their communication with diabetes educators. Future replication studies are needed to confirm the communication outcome patterns found in this study.

Reliability and validity of the Interpersonal Processes of Care Survey (IPC) has been well documented in previous studies (Stewart et al., 1999; Schillinger, et al, 2004; Sudore, et al., 2009). Although the internal consistency of the IPC items for this sample was acceptable and comparable to previous estimates (Schillinger et al., 2004), no additional psychometric testing was performed. Future research and further psychometric testing of the IPC Survey is needed to determine the usefulness of the IPC survey in samples of parents caring for their children.

Although the Rapid Estimate of Adult Literacy in Medicine (REALM) is the most frequently used measurement of health literacy, it relies on word recognition. The complexities of the health literacy construct, defined as the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions for their child, may not be captured adequately by a single measure.

Conclusions

This is one of few studies to suggest that parent health literacy affected communication with diabetes educators. Because this study focused on the communication between parents and diabetes educators in a pediatric diabetes clinic, much of what parents discussed about communication processes related to diabetes education. The findings from this mixed methods study suggest that the communication processes for parents with low and adequate health literacy are neither better or worse but reflect the different learning needs of each group.

Parents with both low and adequate health literacy described very different needs related to the content, pace, and delivery of diabetes education. In essence, parents were struggling with an instructor-driven, set curriculum that, at times, failed to meet their needs. In its place, parents described a learner-driven curriculum that was responsive to their learning needs when they most needed it, making diabetes education relevant to their experience. (Swift, et al., 2009).

Diabetes education programs are driven by curriculum standards with predetermined topics and often are presented in a sequence of teaching/learning lessons (Haas et al., 2012). Consensus guidelines from the American Diabetes Association (Silverstein et al., 2005) and the International Society for Pediatric and Adolescent Diabetes (Swift, 2009) advocate for patient-centered, interactive communication that is paced for the individual learner. Parents may be better served by a learner-driven, problem-based curriculum that allows the content and pace of the education to be guided by participants' questions and concerns; although all aspects of the standard curriculum may be covered (Haas et al., 2012), the order and flow are dictated by the learners (Tang, Funnell, & Anderson, 2006).

Clinical Implications for Diabetes Educators

Diabetes educators may unknowingly contribute to the communication gap between themselves and parents. In a study observing communication between patients and health care providers, an average of 4 jargon terms were used per

visit (Castro, et al., 2007). Although clear communication techniques, for example simplifying language, avoiding jargon, and repeating information, have been linked with improved diabetes control (Rothman et al., 2004), clinicians' use of these strategies in practice remains limited (Schillinger et al., 2003; Schwartzberg, Cowett, VanGeest, & Wolf, 2007). Training programs for diabetes educators should include clear communication techniques.

Traditional models of diabetes education did not meet the needs of the parents in this study. Diabetes educators have an opportunity to create learner-driven diabetes curricula that are responsive and relevant for parents. The findings from this study suggest that diabetes educators should use a variety of teaching/learning strategies to better meet parents' learning needs. Collaboration with experts in education would be a logical next step to incorporate teaching/learning theory and pedagogy into diabetes education. Ultimately, diabetes educators could implement learner-driven diabetes curriculums and a variety of teaching/learning strategies to promote critical thinking such as practice simulation, role play, and Socratic questioning.

Recommendations for Additional Research

The study findings validate the Conceptual Framework of Provider-Patient Communication, providing rich data to the communication process aspect (the conveying and receiving of messages). Additional research may further validate the framework by studying the characteristics and skills of diabetes educators, the communication goals of both the educator and the learner (patient or parent),

and the pediatric diabetes specialty environment. Replication research in additional parent samples and in other settings is needed to confirm or refute the IPC communication outcomes found in this study.

Parents mentioned a variety of teaching strategies that may prove helpful when communicating about diabetes care. Although diabetes guidelines encourage the use of a variety of teaching strategies (Haas, et. Al, 2013), few studies compare different teaching strategies (Albano, Crozet, & d'Ivernois, 2008). Future studies comparing the effectiveness of different teaching strategies would help diabetes educators improve teaching methods when communicating about diabetes care.

Different learning needs related to the content, pace, and delivery of diabetes information calls for a more dynamic, responsive approach to diabetes education. Future research is needed to compare traditional, structured diabetes curriculums to learner-driven, problem-based curriculums for differences in attainment of diabetes knowledge, self-care behaviors, and diabetes control.

Summary

This chapter presented the interpretation of major findings within the context of previous research. The limitations, conclusions, clinical implications, and recommendations for additional research were also discussed.

Appendix A: Table of Variables

Communication Framework	Concept	Conceptual definition	Operational definition
Parent Attributes (predictor)	Health literacy	Degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (IOM, 2004)	Rapid Estimate of Adult Literacy in Medicine (REALM) REALM score=total # correctly pronounced words Low HL $\leq$ 60
Parent External Factors (predictor)	Race/ Ethnicity	Ethnicity: Hispanic, Y/N Race: White, A.A./Black, Asian, Native American	Parent-report of ethnicity/race
	Income	Income levels	Parent-report Under \$15,000 \$15,000- 24,999 \$25,000- 34,999 \$35,000-49,999 \$50,000-74,999 \$75,000-99,999 \$100,000 and over
	Education level	Education level	Parent-report of highest education: Some H.S. or less H.S graduate or GED College graduate or some college Graduate degree
	Diabetes status	Type 1 or type 2 diabetes	Parent report of own diabetes diagnosis
	English language		Parent-report that English is main language at home
Child-diabetes related External Factors (predictor)	Child age	Age in years	Parent-report of child's age
	Child's duration of diabetes	Number of years/months since diagnosis	Parent- report of duration of diabetes
	Child's insulin regimen	Type of insulin regimen	Parent-report: fixed dose, multi-dose, insulin pump therapy
	Child's DM control	A1C levels over past year	Medical chart: A1C past year
	Child co-morbidity	Thyroid or celiac disease	Parent report of child dx of thyroid or celiac disease
	Child DM complications	Diabetes complications	Parent report of child's diabetes

			complications
	# of years attending Diabetes practice	Time in years	Parent report of years attending Cook's practice
Communication process: convey and receive messages (outcome)	Quality of parent-educator communication	:	Interpersonal Processes of Care in Diverse Populations Survey: 5 subscales Five-point Likert scale from always to never
	General clarity	Educator uses vocabulary familiar to parent, speaks clearly and slowly, and confirms that parents understand.	IPC items # 1, 2
	Elicit concerns	Take enough time to elicit most important concerns, help parents feel comfortable enough to discuss concerns, ask about concerns if not volunteered, listen carefully and pay attention	IPC items # 3, 4
	Explain condition	Information provided about condition, changes, in condition, and prognosis.	IPC items # 5, 6
	Explain DM-care	Information provided about taking care of their child at home.	IPC items #7-13
	Decision making	Explains alternative treatment options if there are any, explains how each might differ, discusses pros and cons, considers patient preferences, and arrives at agreeable treatment.	
Qualitative data	Quality of communication	Semi-structured interview. Tell me about a time when you had to learn something you needed to know to take care of your child's diabetes. How did the educator explain things so it was helpful? How about things that were not helpful?. There are words used in diabetes. What do these words mean to you? e.g. dose adjustment, insulin to carb ratio, insulin sensitivity, ketones, target range, A1C	

Appendix B

Demographic Information

Age	_____
Sex	☐ Female ☐ Male
Income	☐ Under \$15,000 ☐ \$15,000- 24,999 ☐ \$25,000- 34,999 ☐ \$35,000-49,999 ☐ \$50,000-74,999 ☐ \$75,000-99,999 ☐ \$100,000 and over
Race/Ethnicity	☐ White ☐ African American/Black ☐ Hispanic ☐ Asian
Diabetes status	Type 1 diabetes ☐ Yes ☐ No Type 1 diabetes ☐ Yes ☐ No
Education	☐ Some high school or less ☐ High school graduate or GED ☐ College graduate or some college ☐ Graduate degree
English language is main language spoken at home?	☐ Yes ☐ No
Child-Related Factors	
Your child's age	_____
Years with diabetes	_____
HbA1c levels from past year	_____
Child's insulin regimen	☐ Fixed insulin doses ☐ Multidose injections ☐ Insulin pump

Appendix C

Rapid Estimate of Adult Literacy in Medicine (REALM)

RAPID ESTIMATE OF ADULT LITERACY IN MEDICINE (REALM)

Terry Davis, PhD, Michael Crouch, MD, Sandy Long, PhD

Chart # _____

Examine date: _____

Name: _____

Birth date: _____

REALM generated reading level: _____

Grade completed: _____

List 1	List 2	List 3
Fat _____	Fatigue _____	Allergic _____
Flu _____	Pelvic _____	Menstrual _____
Pill _____	Jaundice _____	Testicle _____
Dose _____	Infection _____	Colitis _____
Eye _____	Exercise _____	Emergency _____
Stress _____	Behavior _____	Medication _____
Smear _____	Prescription _____	Occupation _____
Nerves _____	Notify _____	Sexually _____
Germ _____	Gallbladder _____	Alcoholism _____
Meals _____	Calories _____	Irritation _____
Disease _____	Depression _____	Constipation _____
Cancer _____	Miscarriage _____	Gonorrhea _____
Caffeine _____	Pregnancy _____	Inflammatory _____
Attack _____	Arthritis _____	Diabetes _____
Kidney _____	Nutrition _____	Hepatitis _____
Hormones _____	Menopause _____	Antibiotics _____
Herpes _____	Appendix _____	Diagnosis _____
Seizure _____	Abnormal _____	Potassium _____
Bowel _____	Syphilis _____	Anemia _____
Asthma _____	Hemorrhoids _____	Obesity _____
Rectal _____	Nausea _____	Osteoporosis _____
Incest _____	Directed _____	Impetigo _____
# of (+) Responses in List 1: _____	# of (+) Responses in List 2: _____	# of (+) Responses in List 3: _____

LEGEND: (+)=Correct (-)=Word not attempted (/)=Mispronounced word

Raw Score: _____

Red Lake Hospital, Red Lake MN 56671
4/98/JMcD

Appendix D

Interpersonal Processes of Care Survey

	Always	Often	Some-times	Rarely	Never	Don't Know	Refused
General clarity							
How often did diabetes educators at this clinic use medical words that you did not understand?	1	2	3	4	5	8	9
How often did you have trouble understanding diabetes educators at this clinic because they spoke too fast?	1	2	3	4	5	8	9
Eliciting Concerns							
How often did diabetes educators at this clinic give you enough time to say what you thought was important?	1	2	3	4	5	8	9
How often did diabetes educators at this clinic listen carefully to what you had to say?	1	2	3	4	5	8	9
Explanation of Condition							
How often did diabetes educators at this clinic give you enough information about your child's diabetes problems?	1	2	3	4	5	8	9
How often did diabetes educators at this clinic make sure you understood your child's diabetes problems?	1	2	3	4	5	8	9
Explanation of Diabetes Care							
How often did diabetes educators at this clinic tell you what you could do to take care of your child at home?	1	2	3	4	5	8	9
How often did diabetes educators at this clinic tell you how to pay attention to your child's symptoms and when to call?	1	2	3	4	5	8	9
How often did diabetes educators at this clinic explain clearly to you how to give your child insulin (when, how much)?	1	2	3	4	5	8	9
How often did diabetes educators at this clinic go over all of the insulin your child is taking?	1	2	3	4	5	8	9
How often did diabetes educators at this clinic give you written instructions about how to give the insulin?	1	2	3	4	5	8	9
How often did diabetes educators at this clinic tell you the reason for taking the insulin?	1	2	3	4	5	8	9
How often did diabetes educators at this clinic tell you about side effects your child might get from the insulin?	1	2	3	4	5	8	9
Decision-Making							
How often did diabetes educators at this clinic ask if you might have any problems actually doing the recommended diabetes plan for your child?	1	2	3	4	5	8	9
How often did diabetes educators at this clinic understand the kinds of problems you might have doing the recommended diabetes plan for your child?	1	2	3	4	5	8	9

Appendix E
Consent Form

**CONSENT FOR RESEARCH AND PERMISSION TO
USE OR DISCLOSE PROTECTED HEALTH INFORMATION**
Parent Health Literacy and Communication with Diabetes Educators in a Pediatric Diabetes
Clinic: A Mixed Methods Approach

CCHCS Department: Diabetes/Endocrinology

**Sponsor: American Association of Diabetes Educators (AADE), Pediatric Endocrine
Nursing Society (PENS), Sigma Theta Tau International (STTI)**

**Research Team: Principal Investigator: Andrea Smith PhD, RN CPNP
Sub-Investigator: Carol J. Howe, RN MSN CDE**

Telephone #: 682-885-3383

This form is an invitation to take part in a research project. Before deciding to join us, it is important for you to understand:

- What the research project is and why we invited you to join us.
- How we do the research project.
- Related risks or problems.
- How this study helps you.
- Costs and payments.
- What happens to your research records and information
- Your rights and responsibilities

Please take your time reading this form and know that you are not alone if parts of it seem confusing. Talking to your doctor, family, or friends often helps. It also helps to write down your questions and concerns.

How we present information

People learn in different ways. We explain this information using discussions, diagrams, pictures, and handouts. Please let us know if some of these ways are easier for you to understand.

For parents reading this form

This information is for our adult participants. It is also for parents or guardians of children under 18 years of age. If you are a parent or guardian, the words "you, your, I, or me", in this form, refer to your child.

Who Are We?

Different groups of people make up our research project. You may meet one or all of these people during the study.

The Research Team:

1. Principal Investigator (PI): The primary person who oversees the research study. She will answer any questions you may have about the research study.
2. Sub-Investigator (Sub-I): Other health care providers involved with the research study. Like the PI, they can answer any questions you may have about the research study.

Why Are We Doing this Research?

The purpose of this research is to understand how parents learn about diabetes and how you talk with diabetes educators. We are asking you to take part in this research because you are a parent of a child with type 1 diabetes. About 162 parents will take part in this research.

How Do We Select Participants?

We want to talk with parents that:

- Have a child with type 1 diabetes
- Have met with a diabetes educator in the last year.
- Are able to speak English because we will be doing the questionnaire and interview in English

Standard Tests and Procedures

Your child has routine hemoglobin A1C tests done for his or her diabetes. We will take down your child's hemoglobin A1C levels for the past year. We are not doing any additional tests on your child for this research study.

Research Participation

If you choose to be in this study, here is what will happen:

1. The researcher will read and discuss consent for the study with you.
2. After you sign the consent, the researcher will go over a questionnaire with you. This will take about 10 minutes. The questionnaire includes:

- general questions about you and your child such as your age, race, income, years of education, and how long your child has had diabetes, what insulin regimen he uses, and whether he/she has any other conditions.
 - questions about your communication with the diabetes educators
 - list of medical words for you to read
3. You may also be asked to stay for a longer interview with the researcher. The researcher wants to learn about parent's experience talking with diabetes educators.
- This interview will be done in a private room and audio recorded.
 - The interview lasts about 30 minutes.
 - At the completion of the interview, the researcher will ask you for contact information. The researchers may want to contact you for a short interview if they need more information.
4. The researchers record your child's hemoglobin A1C levels from the past year from the medical record.

Length of Research Study

This research study is expected to last 1 year.

Taking part in this research study is voluntary.

- You may choose not to take part.
- You may stop at any time.
- If you decide to stop, Cook Children's will continue to provide the standard (regular) medical care, for your child, just as before.

Risks & Side Effects of this Research Study

Possible risks and side effects are a part of all research studies. We can list the risks and side effects we know about, but there may be others we do not know about at this time. The known risks and side effects associated with this research study are: you may feel uncomfortable answering the questionnaire or interview questions because you are talking about your child's diabetes.

Will this Research Study Help Me?

You may receive the following benefits from this research:

- Like this opportunity to talk about your child with diabetes
- Learn how much you know about your child's diabetes
- Think about how you talk with your diabetes educator.

However, this research study may not help you at all. Your research team cannot guarantee that this study will help your child's diabetes.

We hope the information we learn from this research will help diabetes educators know how to improve their work with future patients with diabetes and their parents.

What Are My Other Choices?

1. You may decide not to join this study.
2. If you decide not to join this study, your child will continue to receive medical care for their diabetes at Cook Children's.

Remember: You can always choose to stop taking part in the research study. If you want to stop, your PI and/or a member of the research team will explain how you can do this.

Costs and Compensation

You will not be responsible for any costs associated with taking part in this research study

You (or your insurance company) are still responsible for the costs of standard (regular) medical care during this research study.

Standard (regular) medical care: This is the usual medical care you would need for your child's diabetes if you were not taking part in this research study.

If you have any questions or concerns about the cost of your care, please talk with our CCHCS financial counselors or your investigator about this.

Emergency Medical Treatment

Emergency medical treatment is available if you become injured or ill because of this research study. If you are injured as a result of taking part in this research study:

Cook Children's has not set aside any funds (money) to pay you in case you are injured as a result of taking part in this research study. In addition, Cook Children's has not set aside any funds to pay for your emergency medical treatment or ongoing medical care related to this research study. You or your insurance company may be responsible for costs associated with any necessary emergency medical treatment.

If you need continuing medical care and/or hospitalization, you or your insurance company may be responsible for these costs.

Payment for being in this Research Study

1. Each research study is different. Some studies pay (or reimburse) participants for their time and effort related to taking part in a research study. And some do not.

2. You will be reimbursed \$10.00 for taking part in this research. You will receive this reimbursement today. Reimbursement is considered to be a refund paid to you, for the expenses that you have already incurred (covered) as a result of taking part in this study, i.e., such as time taken off from work specifically for this study, gas expenses, traveling to and from the institution, parking costs, etc. This money will be paid to your parent (if you are under 18) and to you (if you are 18 or older).

If you are receiving payment or reimbursement on this study, you will need to understand the information discussed in the “Public Assistance” section below. Also, you will need to talk with a Cook Children’s Financial Counselor if you have any questions about this information. Please tell your Clinical Research Coordinator if you would like to talk with a Cook Children’s Financial Counselor or call 682-885-4000 and ask to speak to a Financial Counselor.

Public Assistance Programs (Social Security, Medicaid, Medicare):

You have been told how much **extra money** you can make (by your public assistance program) and still receive public assistance. If you make more than this amount, the government could remove you from the program. Research money that covers your costs is not usually considered to be **extra money**. There is a new law called the “Improving Access to Clinical Trials” Act that you should be aware of. If you are taking part in a research study which focuses on a rare disease such as Cystic Fibrosis, Muscular Dystrophy, or other rare disease or condition, this law makes it possible for you to receive a certain amount of **extra money** and still qualify for your public assistance program.

If you are receiving public assistance from any type of program, please speak to a Cook Children’s Financial Counselor. The Financial Counselor can tell you if these payments could cause you to become ineligible (or not to qualify) for the public assistance program.

Will You Keep My Records Private?

The Health Insurance Portability and Accountability Act (HIPAA) limits the use and disclosure of your private Protected Health Information (PHI). This means by law, we cannot share your personal or medical information.

However, by signing this consent form, you are giving us permission to share this information. You are allowing us to give out some of your private records. It is important for you to know what information we will share. This information may include:

- History and diagnosis of your disease
- Laboratory test results
- Follow-up information about your general health
- Status of your disease

Other Information that May be Used or Shared

This includes any information about your physical or mental health, your health care, or payment for your health care. It also includes your:

- Name
- Birth date

- Race/ethnicity
- Gender
- Diagnosis
- Disease Status
- Zip Code
- Race/Ethnicity
- Diagnosis Date

Who Will See My Information?

CCHCS will protect your private information. However, once you give us permission, we cannot absolutely guarantee this privacy, nor guarantee that your private information will remain protected. For example, the law may require us to give information to the courts or the health department. Depending on the study, your private health information (PHI) may be shared with several groups including:

These can include:

- CCHCS Institutional Review Board (IRB) – a selected team of people who make sure that the rights of research participants are protected and respected.
- CCHCS Legal and Compliance Departments.
- Federal Food and Drug Administration (FDA).
- Federal Office for Human Research Protections (OHRP)

How Will You Use My Private Information?

If you give us permission, the researchers may use or share your private health information (PHI) for this research study. The researchers may report their findings about this research study in scientific journals or meetings, but these reports will not identify you.

What If I Do Not Give Permission?

If you refuse to give permission, you can still get standard, non-research health care from CCHCS. But, you would not be able to take part in this research study.

Can I Cancel My Permission?

You have the right, at any time, to cancel permission for the researchers to use or share your private health information (PHI). If you cancel your permission, you can still get standard, non-research health care from CCHCS. But, you would not be able to take part in this research study. To cancel permission, you must write to the Principal Investigator (PI) or the CCHCS Privacy Officer, at 801 Seventh Avenue, Fort Worth, TX, 76104. Or, you may email the CCHCS Privacy Officer at compliance@cookchildrens.org

How Long Can You Use or Share My Information?

There is no time limit for using your information: Unless you cancel your permission in writing, the Cook Children's researchers can continue to use or share your information indefinitely.

If you cancel your permission: As soon as you cancel your permission, we will stop sharing information. However, any information we shared before you withdrew your permission, is not affected. Cancelling permission does not cancel the information we have already used or shared. If you wish to cancel your permission at some point during this study, it is possible that we will not be able to identify your information due to the confidentiality protections in place. However, if any link to your information and your identity remains, your information will be removed from the study and any and all links to your identity would also be removed.

Once you cancel permission, the researchers cannot:

- use your information for anything new
- share it

What Are My Rights as a Research Participant?

1. You have the right to find out about the release of your Protected Health Information.
2. You have the right to withdraw your participation in the research at any and all levels at any time.
3. You have the right to have all your questions and concerns addressed and answered to the best of our ability.
4. You have the right to any new information that becomes available during your participation in this research that may affect your health or willingness to continue in the research.

What Are My Responsibilities as a Research Participant?

The research team will monitor you closely while you are in this research. They will watch for any problems that may require additional medical care. It is your responsibility to do the following:

1. Ask questions about anything you do not understand.
2. Keep appointments.
3. Follow instructions.
4. Tell the research team if your telephone number changes.

What if I Have Questions or Problems?

If you have questions about this research study, you may call the Principal Investigator or any member of the research team at 215-805-8345. If you are injured, you may call the Principal Investigator or any member of the research team at 682-885-3383.

For information about your rights as a research participant, you may call the Cook Children's Institutional Review Board (IRB) at 682-885-1764.

A representative of the IRB may call you and ask about your experience with this research study. They want to make sure your rights as a research participant have been protected and respected. You have the right to answer or refuse to answer any questions the IRB may ask.

STATEMENT OF CONSENT and AUTHORIZATION

Your signature below means that you want (consent) to take part in this research study. It also means that you give permission (authorize) the CCHCS researchers to use and share (disclose) any of your Protected Health Information (PHI) that is related to this research.

You should not sign this form until you have had the opportunity to read it (or have it read to you) and have all your questions and concerns answered. You should not sign this form unless you have made a free and voluntary choice to be in the research and to give permission for your PHI to be used and shared.

Taking part in the research and giving permission for CCHCS researchers to use and share your PHI are voluntary. Refusing to take part or to give your permission will not result in any loss of benefits to which you are otherwise entitled. You will still be able to get standard, non-research health care from CCHCS.

You may withdraw from the research or cancel permission for your PHI to be used or shared at any time. Withdrawing from the research or canceling your permission will not result in any loss of benefits to which you are otherwise entitled. You will still be able to get standard, non-research health care from CCHCS.

Your signature below means:

- You have read the information above (or it has been read to you)
- You have received answers to your questions at this time
- You have freely decided to take part in this research. If you take part in the interview, you are willing to be re-contacted if the researchers need more information.
- You have freely given permission for CCHCS researchers to use or share your Protected Health Information for the purposes of this research.
- You are not giving up any of your legal rights.

You will receive a copy of this form.

Printed Name of Parent Participant

Signature of Parent Participant

Date

Printed Name of Child Participant

Signature of Parent Providing Permission for Child Participant

Date

PRINTED NAME OF
PERSON OBTAINING CONSENT

SIGNATURE OF PERSON
OBTAINING CONSENT

DATE

PRINTED NAME OF WITNESS
(IF REQUIRED)

SIGNATURE OF WITNESS
(IF REQUIRED)

DATE

NOTE:

The Witness Signature above indicates that the witness has observed (Please check one of the following):

- ☐ The informed consent conference involving the participant and the person obtaining consent.
- ☐ The signing of this form by the participant (or legally authorized representative) and the person obtaining consent.
- ☐ Both of the above.

OR:

- ☐ The Witness Signature was not obtained because the subject and/or legally authorized representative are fluent in English and are not illiterate.

NOTE: Informed consent must be obtained in language understandable to the subject. This requires use of either (i) a full, translated informed consent document approved by the CCHCS IRB, or (ii) a translated, IRB-approved "short form" a translator and witness for the consent process.

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Biographical Information

Carol Howe has been a clinical nurse specialist and diabetes educator, working with children and families living with diabetes for over 20 years. Howe holds a Master of Science in Nursing, a Bachelor's of Science in Nursing, and a Bachelor's of Arts from the University of Pennsylvania. Howe has been a principal or co-investigator for survey, intervention, and qualitative research related to children with type 1 diabetes; her research has focused on barriers to self-care including needle phobia, eating disorders, and patient-provider relationships. Her dissertation research examined and explored how parent health literacy affected communication with diabetes educators, using a mixed methods approach. Howe received grants for her dissertation research from the American Association of Diabetes Educators, the Pediatric Endocrine Nursing Society, Sigma Theta Tau International, and the Kyba Fellowship. She plans to expand her program of research as she moves into a full time faculty position. Howe is a member of the Research Committee of the Pediatric Endocrine Nursing Society and the National Youth Strategies Committee of the American Diabetes Association.