Relationship of Caregiver Health Literacy to Readiness for Discharge Following a Child's Hospitalization

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Abstract

The field of health literacy research is relatively new. As a result, there is a lack of studies on health literacy that relate specifically to the pediatric population. Low health literacy in America is estimated to characterize at least one-third of the adult population. Many of these adults are parents, and inadequate caregiver health literacy has been shown to negatively affect the health of children. With shorter hospital stays now a part of the modern health care system, it is crucial that nurses prepare caregivers to care for their children after hospital stays. The purpose of this study was to determine if caregivers' health literacy level affects their perception of readiness for discharge following the hospitalization of a child. The relationship of caregiver health literacy to caregivers' post-discharge coping and utilization of support and health care services for the child also was explored. Participants recruited for the study were caregivers of patients admitted to an 11-bed, general medical/surgical pediatric unit in central Virginia between November 2014 and March 2015. Data collection took place on the pediatric unit while the child was hospitalized and by telephone after the child's discharge. In this study, caregiver health literacy was not significantly related to readiness for hospital discharge, post-discharge coping difficulty, or utilization of health services after hospital discharge. Further research is needed to determine if there are identifying characteristics of caregivers who report being unready for discharge, and who have difficulty coping after a child's hospitalization, as this information can be used to guide the development of nursing interventions to improve caregivers' readiness for discharge.

Signature Page

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Dedication

The work contained within these pages would not have been possible without the support of many. First and foremost, I am grateful for the encouragement of my family and friends. Throughout my years of doctoral study, my husband, Chris, and our daughters, Abigail and Arynn, have been patient and understanding, and have cheered me along when I needed it most. My extended family members have been constant supporters of my educational pursuits from the very beginning. I would like to thank my friends and nursing colleagues who have helped me in countless ways; I am especially appreciative to those who have experienced firsthand what it is like to earn a doctorate, as they have provided special encouragement along the way. To my PhD classmates, “thank you” seems so inadequate for all that you mean to me; I have fond memories of late-night study sessions for statistics, lunch “therapy” sessions in the doctoral student lounge, and countless other shared experiences.

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CHAPTER I

Introduction

Background and Significance of the Study

Health literacy, as defined by the Affordable Care Act of 2010, is the “capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions” (Koh et al., 2012, p. 434). Although the term health literacy has been used for more than 40 years (since 1974), health-related disciplines have taken awhile to recognize the many implications of the term. Few publications appeared on the topic of health literacy prior to the early 1990s. In 1992, the Robert Wood Johnson Foundation funded a two-year study that is now considered the seminal work on health literacy (Speros, 2005). In this study, the first to assess individuals’ literacy skills as they relate to a health care setting, researchers found that many of the adult participants did not understand instructions regarding a routine radiographic procedure written at the fourth-grade level. Respondents had difficulty comprehending directions related to medications and did not grasp the information provided regarding scheduled follow-up visits (Williams et al., 1995). Based on these findings, Williams et al. concluded that inadequate functional health literacy can lead to “decreased compliance, poorer health outcomes, or adverse reactions among patients” (pp. 1680–1681).

Since the 1995 study by Williams et al., numerous other studies have been conducted, expanding on their work. As a result of this burgeoning scholarship, the field of health literacy has grown significantly. No longer only the interest of clinicians and researchers, health literacy has attracted the attention of federal policymakers, who recognize that “improved health literacy has the potential to help address issues of health care access, quality, and cost” (Koh et al., 2012, p. 434).

The year 2010 was a particularly important time in terms of increasing the attention given to issues related to health literacy. During that year, the Affordable Care Act (also known as the health care reform law of 2010); the National Action Plan to Improve Health Literacy, produced by the U.S. Department of Health and Human Services; and the Plain Writing Act of 2010 were all instituted (Koh et al., 2012). Health literacy remains a concern of many today, and improving the health literacy of the population is a focus of Healthy People 2020, an initiative that consists of 10-year national objectives to improve the health of all Americans (U.S. Department of Health and Human Services, n.d.).

Statement of the Problem

Because health literacy research is still relatively new (Weld, Padden, Ramsey, & Garmon Bibb, 2008), there is a lack of studies that specifically relate to the pediatric population. Most of the existing research has focused on adult patients (Betz, Ruccione, Meeske, Smith, & Chang, 2008). Current data regarding the prevalence of low health literacy are derived from the 2003 National Assessment of Adult Literacy (NAAL). In that survey of more than 19,000 adults, participants’ health literacy was characterized as either below basic, basic, intermediate, or proficient. Twenty-two percent of respondents demonstrated basic health literacy skills, while another 14% exhibited below basic abilities on the health literacy tasks that comprised the assessment (Kutner, Greenberg, Jin, & Paulsen, 2006). Combining these categories, this means more than one-third of the adult population has limited health literacy. Since many of those adults are parents, this finding is potentially significant in terms of its implications for children. As Betz et al. (2008) explained: “Adequate parental literacy is necessary for appropriate management of the child’s health needs. . . . Inadequate health literacy can result in improper medication administration, missed appointments, and incorrect performance of care at home . . . thereby adversely affecting the child’s health and treatment outcomes” (p. 231).

Just as a child’s hospitalization is recognized to be a stressful experience for affected children and their parents (Ball, Bindler, & Cowen, 2012), discharge from the hospital has become increasingly complex in the current health care environment (Kornburger, Gibson, Sadowski, Maletta, & Klingbeil, 2013; Weiss et al., 2008). The transition from hospital to home requires significant preparation as inpatient pediatric nurses strive to equip parents with the knowledge and skills necessary to care for their children after leaving the hospital (Kornburger et al., 2013; Lerret, 2009; Weiss et al., 2008).

Although nurses are the ones largely responsible for teaching parents of hospitalized children about discharge, it is essential to determine caregivers’ ability even to comprehend the nurses’ instructions. To date, no known research has specifically examined the relationship of health literacy to readiness for hospital discharge. A review of the literature yielded one study that described an educational intervention designed for nurses that included the concepts of “teach-back” and health literacy to improve the hospital discharge process. Nurses were asked before and after the intervention if they knew the meaning of the term “health literacy.” Prior to receiving the education incorporated into this evidence-based project, 39 of the 58 participating nurses (67.2%) were familiar with the term health literacy. After the intervention, 92.5% of respondents had a better understanding of this concept as it relates to hospital discharge (Kornburger et al., 2013). Findings from that study, coupled with existing research on the consequences of inadequate health literacy, support the need for additional research to examine the relationship between health literacy and readiness for hospital discharge.

Statement of Purpose

The purpose of this study was to determine if caregivers’ health literacy level affected their perception of readiness for hospital discharge following the hospitalization of a child. In this study, caregivers’ health literacy and perception of readiness for hospital discharge were assessed using instruments with established psychometric properties: the Self-Reported Health Literacy Measure and the Readiness for Hospital Discharge Scale—Parent Form. The relationship of caregiver health literacy to caregivers’ post-discharge coping and utilization of support and health care services for the child was explored as well.

Research Questions and Hypotheses

Research Question 1: Is there a relationship between caregiver health literacy and the caregiver’s perception of readiness for hospital discharge?

Hypothesis 1: There is a relationship between caregiver health literacy and the caregiver’s perception of readiness for hospital discharge.

Research Question 2: Is there a relationship between caregiver health literacy and caregivers’ post-discharge coping?

Hypothesis 2: There is a relationship between caregiver health literacy and caregivers’ post-discharge coping.

Research Question 3**:** Is there a relationship between caregiver health literacy and the caregiver’s utilization of health services for the child after hospital discharge?

Hypothesis 3: There is a relationship between caregiver health literacy and the caregiver’s utilization of health services for the child after hospital discharge.

Significance to Nursing

Preparing for discharge begins soon after hospital admission. Nurses have a tremendous responsibility in regards to helping patients and their families get ready to return home (Ball et al., 2012; Lerret, 2009). Although not all children will have ongoing health care needs following a hospitalization, “families still need support and education, as they may continue to be anxious or stressed over their child’s hospitalization” (Ball et al., 2012, p. 286).

Nurses should not merely provide parents with information about diagnoses, medications, and treatments; rather, nurses should ensure parental understanding of the material covered prior to hospital discharge (Ball et al., 2012; Kornburger et al., 2013). A recent study published in the *Journal of Pediatric Nursing* described how nurses can use the “teach-back” process to verify understanding of information taught in order to facilitate the transition from hospital to home for patients and their families. The teach-back process consists of four steps: the nurse teaches the information; the patient or caregiver repeats the instructions back to the nurse in his/her own words (or performs a return demonstration of the skill); if there are errors, the nurse corrects or clarifies the patient’s/caregiver’s understanding of the information; the nurse asks if the patient/caregiver has any other questions (Kornburger et al., 2013). Researchers like Kornburger et al. (2013) have explained the rationale for assessing health literacy when preparing for hospital discharge: “For caregivers with low health literacy skills, discharge from the hospital can be confusing and overwhelming which can result in misunderstood instructions and non-compliance with the discharge plan” (p. 282).

To date, no nursing studies have explored the relationship between a caregiver’s health literacy and the caregiver’s perception of readiness for hospital discharge. Findings from this study will contribute to what is known about the health literacy of parents of hospitalized children and, ultimately, help nurses better prepare pediatric patients and their caregivers for the transition from hospital to home.

CHAPTER II: LITERATURE REVIEW AND THEORETICAL FRAMEWORK

Health Literacy

Definition of Health Literacy

Health literacy is defined various ways throughout the literature. Many writers and researchers have adopted the definition used by the Institute of Medicine (IOM) in a 2004 report entitled *Health Literacy: A Prescription to End Confusion* (Bass, 2005; Koh, Brach, Harris, & Parchman, 2013; Rudd, Anderson, Oppenheimer, & Nath, 2007; Weld et al., 2008). In the definition developed for the National Library of Medicine and used by the IOM, health literacy is characterized 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” (Ratzan & Parker, 2000/2004, p. 32).

Relationship Between Literacy and Health Literacy

Although the terms literacy and health literacy are related, they are not synonymous (Bass, 2005). The U.S. Department of Education’s National Center for Education Statistics proposes that there are both conceptual (task-based) and operational (skills-based) definitions of literacy. According to the National Assessment of Adult Literacy, “literacy is the ability to use printed and written information to function in society, to achieve one’s goals, and to develop one’s knowledge and potential” (NAAL, n.d., para. 1). Speros (2005) highlighted the distinction between literacy in general and *health* literacy: “A person’s ability to read and comprehend prescription bottle labels, appointment slips, and health instructions, or their health literacy level, may be significantly worse than their general literacy” (p. 634).

Health Numeracy

The concept of numeracy frequently appears within the body of literature on health literacy. In the past, health numeracy has often been viewed as an aspect of health literacy. However, researchers are increasingly recognizing the need to establish numeracy as a separate concept (Apter et al., 2006; Golbeck, Ahlers-Schmidt, Paschal, & Dismuke, 2005). Health numeracy is defined as “the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions” (Golbeck et al., 2005, p. 375).

Just as health literacy and literacy are different, there are also important distinctions between health literacy and health numeracy. Golbeck et al. (2005) identified four functional categories of health numeracy: basic, computational, analytical, and statistical. The descriptions of these categories indicate that a variety of skills comprises health numeracy, which is one of the primary reasons that a separate definition of this concept is required. In recent studies, researchers have separately evaluated literacy and numeracy skills. In a study on parental understanding of infant health information, Kumar et al. (2010) found that while 99% of participants had adequate literacy skills, only 17% had numeracy skills above a ninth-grade level. In other words, participants’ ability to engage well with more analytically and mathematically rigorous material lagged behind their ability to read and understand basic writing. Research by Apter et al. (2006) regarding adults with asthma suggested that numeracy skills should be evaluated separately from health literacy. These findings illustrate the need to consider health numeracy as a separate concept when assessing health literacy and subsequently designing interventions based on research findings.

The Importance of Health Literacy

As mentioned in Chapter I, the concept of health literacy was first introduced in 1974, but not until the 1990s did the topic attract much attention from medical professionals and others in health-related disciplines (Speros, 2005). In the previously mentioned seminal study on health literacy (funded by the Robert Wood Johnson Foundation over a two-year period starting in 1992), researchers found that 22.0% to 61.7% of participants had inadequate or marginal functional health literacy (Williams et al., 1995). Since those findings were disseminated, research has flourished, and health literacy has moved to the forefront of multiple audiences, from health care to governmental agencies, including both public and private organizations (Koh et al., 2012). As one group of researchers summarized, “Health literacy is central to multiple health system priorities, including quality, cost containment, safety, and patients’ involvement in health care decisions” (Parker, Ratzan, & Lurie, 2003, p. 147).

Risk Factors for Low Health Literacy

As studies of health literacy have proliferated, investigators have sought to determine the factors that increase the likelihood of lower health literacy. Determination of these characteristics is essential in the development of interventions to improve patient care and outcomes (Martin et al., 2009). In the landmark study by Williams et al. (1995), age and education were identified as the two main determinants of health literacy; furthermore, these two factors were found to be independent predictors of low levels of health literacy. Martin et al. (2009) expanded on that work with a study specifically designed to identify predictors of health literacy; they found that, "as expected, older individuals, minorities, those with less education, lower incomes, those who were divorced, widowed or separated, and those who had been living in the U.S. for fewer years had lower mean health literacy" (p. 1213). The National Network of Libraries of Medicine (NN/LM) has reiterated the findings of both Williams et al. and Martin et al., stating on its website that older adults, immigrants, minorities, and persons with low income are considered vulnerable populations in terms of being at risk for low health literacy (NN/LM, 2016).

Low Health Literacy as a Health Disparity

Even though there are known risk factors, identifying persons with low health literacy can be challenging. In one study, Kelly and Haidet (2007) found that physicians overestimated patients' literacy levels by as much as 54%, particularly in minority patients. Misjudging patients' literacy can negatively affect physician–patient communication, which may, in turn, result in poor health outcomes for patients. Patients who have low health literacy are often reluctant to disclose their difficulties due to feelings of shame (Parikh, Parker, Nurss, Baker, & Williams, 1996). Based on a systematic review of the literature (24 studies total), Easton, Entwistle, and Williams (2010) identified persons who can communicate verbally but struggle with written language; they labeled this group the "hidden population" of people with low literacy. Their work revealed that persons with low functional health literacy are at risk for poor health because health care providers may not recognize their literacy deficits. These authors discussed "the stigma associated with low literacy skills and the coping mechanisms implemented by those with low literacy" as a barrier to including these individuals in research (Easton et al., 2010, p. 9). Although finding ways to include this "hidden population" in research may not be easy, such research is nevertheless needed to tackle the stigma associated with low health literacy—and remedy the problems that result from overlooking this population. As one team of researchers put it, "A better understanding of the stigma associated with health literacy is a worthy goal on its own, but it will also increase knowledge of a factor that underlies a variety of other health issues and contributes to poorer health as patients fail to seek care" (Mackert, Donovan, Mabry, Guadagno, & Stout, 2014, p. 696).

Instruments Used to Assess Health Literacy in Clinical Research

The Agency for Healthcare Research and Quality (AHRQ) report *Health Literacy Interventions and Outcomes: An Updated Systematic Review* includes a comprehensive list of 15 instruments that assess health literacy. Of these 15 measures, 10 have been validated and 5 have been partially validated. Twelve of the instruments have a health focus while the other three appraise general literacy. Each measure has a different number of items, and the amount of time required to complete the tests also varies, from 1–2 minutes for shortened versions of some measures to as much as 70 minutes for longer instruments. Another difference in the measures relates to the methods used to assess health literacy. Some of the approaches employed include demographics, word recognition and pronunciation, reading comprehension, word problems, and a quantitative skills test.

Of the 15 instruments in the AHRQ report, the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA) are the 2 most commonly used to measure health literacy (Berkman et al., 2011). A systematic review of the health literacy literature supported the finding that the REALM and TOFHLA are used most often. Of the 19 studies included in the review, 11 used the TOFHLA or its shortened version, and 6 used the REALM (Herndon, Chaney, & Carden, 2011). Two additional instruments, the Newest Vital Sign (NVS) (Weiss et al., 2005) and the Self-Reported Health Literacy Measure (Chew, Bradley, & Boyko, 2004), have also been found useful in assessing health literacy in the clinical setting.

Rapid Estimate of Adult Literacy in Medicine. The REALM was originally developed in 1991 with 125 items, which took 5 minutes to administer and score. In an effort to make this instrument more practical for use in busy health care settings, a shortened, 66-item version, requiring only 1–2 minutes to complete, was developed (Davis et al., 1993). The revised REALM (or REALM-R) is a reading recognition test that requires those taking the assessment to pronounce a variety of commonly used medical terms. This measure of health literacy had sound psychometrics when evaluated alongside three other instruments as well as excellent test-retest reliability. The REALM-R is regarded as a screening tool, as it yields an estimated grade range (third grade and below, fourth to sixth grade, seventh to eighth grade, or ninth grade and above) rather than a specific reading grade level. Also, the results of this measure do not necessarily indicate understanding of the terms, only an ability to pronounce the words (Davis et al., 1993).

Test of Functional Health Literacy in Adults. The TOFHLA was the first tool developed for measuring functional health literacy. “Adequate functional health literacy means being able to apply literacy skills to health-related materials such as prescriptions, appointment cards, medicine labels, and directions for home health care” (Parker, Baker, Williams, & Nurss, 1995, p. 537). Creation of this tool was based on an extensive review of a variety of health care materials, including patient education information, prescription labels, patient registration forms, and instructions for medications and diagnostic tests. Unlike previous instruments like the REALM (which only requires pronunciation of medical terms), the TOFHLA measures both comprehension and numeracy as well. Specifically, the TOFHLA consists of 50 reading comprehension items and 17 items testing numerical ability. The test takes up to 22 minutes to complete and is available in English and Spanish. Psychometric testing has shown the TOFHLA to be a reliable and valid instrument for assessing health literacy and numeracy (Parker et al., 1995). In an effort to reduce the amount of time required for the TOFHLA, a shortened version (the S-TOFHLA) was developed and tested. The revised instrument requires only 12 minutes to complete (Baker, Williams, Parker, Gazmararian, & Nurss, 1999).

The Newest Vital Sign. The NVS tool is “the first literacy screening test available in both English (NVS-E) and Spanish (NVS-S) that can be administered in approximately 3 minutes” (Weiss et al., 2005, p. 520). The test consists of a nutrition label and six questions that assess respondents’ ability to read and interpret information on a label. The idea behind creating the NVS was to develop an instrument that can quickly and accurately screen for limited health literacy in primary health care settings. Psychometric testing was performed on the NVS and the results compared to psychometrics on the TOFHLA, which is an older, established instrument for evaluating health literacy. The NVS-E had good internal consistency (Cronbach’s $\alpha = 0.76$) and criterion validity ($r = 0.59$, $p < .001$). The NVS has a scoring range of 0–6, with one point given for each question answered correctly. Persons who score less than 4 on the

NVS may have limited literacy (Weiss et al., 2005). The NVS has been used increasingly in research involving adults and children (Driessnack, Chung, Perkhounkova, & Hein, 2014; Johnson & Weiss, 2008; Shah, West, Bremmeyr, & Savoy-Moore, 2010).

The Self-Reported Health Literacy Measure. This measure consists of three questions that have been shown to effectively screen for inadequate health literacy. Prior to the development of this instrument, many of the existing tools for screening for and evaluating health literacy were neither practical for use in busy clinical settings nor able to be used widely with large numbers of people (Chew et al., 2004). The questions that comprise this instrument are: (1) “How often do you have someone help you read hospital materials?”; (2) “How confident are you filling out medical forms by yourself?”; and (3) “How often do you have problems learning about your medical condition because of difficulty understanding written information?” (Chew et al., 2004, p. 590). Chew and colleagues conducted initial validation studies of this measure with persons seeking care at U.S. Department of Veterans Affairs (VA) facilities (Chew et al., 2004; Chew et al., 2008). Subsequent research found that a single question from this tool—the second one in the list above (“How confident are you filling out medical forms by yourself?”)—can be used alone to screen for limited health literacy (Sarkar, Schillinger, Lopez, & Sudore, 2010; Wallace, Rogers, Roskos, Holiday, & Weiss, 2006). Additionally, use of this one question combined with a total score on the full three-question measure can effectively differentiate those who have adequate versus inadequate health literacy among English-speaking as well as Spanish-speaking individuals (Sarkar et al., 2010). The Self-Reported Health Literacy Measure has been evaluated alongside both the S-TOFHLA (Chew et al., 2004; Sarkar et al., 2010) and the 66-item REALM (Chew et al., 2008; Wallace et al.,

2006) to ensure that this instrument can be used to screen effectively for health literacy in various populations.

After reviewing the instruments most commonly employed to assess health literacy in the clinical setting, the Self-Reported Health Literacy Measure was chosen for use in this study. The tool can be completed quickly by parents and effectively assesses their health literacy. This instrument was found comparable to other, more extensive measures of health literacy but was ultimately chosen because it consists of only three questions and thus reduced the time required of study participants.

Parental Health Literacy

As already discussed, health literacy is an important issue that has gained increasing attention in recent years. Despite the newfound interest in this topic, most of the related research to date has involved adults (Betz et al., 2008; Rothman et al., 2009). More recent studies have focused on health literacy in the pediatric population—in particular, by examining parental health literacy, since parents are the persons primarily responsible for providing care to their children (DeWalt & Hink, 2009; Kumar et al., 2010; Morrison, Myrvik, Brousseau, Hoffmann, & Stanley, 2013; Sanders, Federico, Klass, Abrams, & Dreyer, 2009; Tran, Robinson, Keebler, Walker, & Wadman, 2008). Forrest, Simpson, and Clancy (1997) identified four issues unique to child health that emphasize the need for pediatric-specific research focused on the relationship between health literacy and quality of care. These four issues, or the “4 D’s” as they are called in the literature, are “the developmental change of children over time; dependency on parents or adults; differential epidemiology of child health; and the different demographic patterns of children and their families” (Rothman et al., 2009, p. S315).

Several studies have investigated the relationship between parental health literacy and the care of children with chronic illnesses. Specifically, these studies involved parents of pediatric patients who had a diagnosis of asthma or insulin dependent diabetes (now better known as type 1 diabetes) (DeWalt, Dilling, Rosenthal, & Pignone, 2007; Janisse, Naar-King, & Ellis, 2010; Macy, Davis, Clark, & Stanley, 2011; Shone, Conn, Sanders, & Halterman, 2009). Parental health literacy is a concern that spans diagnoses and pediatric health care settings. Existing studies have been conducted in emergency departments (Macy et al., 2011; Morrison et al., 2013; Sanders, Thompson, & Wilkinson, 2007; Tran et al., 2008) and pediatric clinics (DeWalt et al., 2007; Kumar et al., 2010; Moon, Cheng, Patel, Baumhaft, & Scheidt, 1998), but no studies have been found that assess the health literacy of parents whose children are admitted to an inpatient pediatric unit.

Parental Health Literacy and Child Health Outcomes

Because parental health literacy has only recently moved to the forefront as a pediatric nursing issue (Betz et al., 2008), the published literature lacks consensus on the relationship between parental health literacy and child health. The conflict in information is readily apparent in two systematic reviews of the literature that incorporated numerous studies on the topic (DeWalt & Hink, 2009; Sanders et al., 2009). Some researchers have found that children of parents who have low levels of health literacy experience negative health outcomes. DeWalt et al. (2007) concluded that low parental health literacy negatively affects the care of children with asthma. Additionally, Kumar et al. (2010) found that “many caregivers had difficulty understanding basic health information for the care of infant children” (p. 314). On the other hand, Sanders et al. (2007) concluded “there were no differences in health care use or cost between children of caregivers with low health literacy and children of caregivers with adequate health literacy” (p. e86). This result upheld an earlier conclusion of Moon et al. (1998) that there is no relationship between parental health literacy and either utilization of preventive health services or parents’ ability to comprehend and follow health care instructions. Still other research has indicated a potential link between parents’ health literacy and child health. Janisse et al. (2010) concluded that limited health literacy may impair parents’ abilities to follow prescribed regimens for diabetes management. The lack of agreement about the effects of parental health literacy on the health of children supports the need for further research in this area.

In addition to the above-mentioned studies relating parent health literacy to child health outcomes, other researchers have also evaluated the correlation between parental health literacy and health care matters related to providing care for children, including preventive care practices (Sanders et al., 2009), health care utilization (Herman & Jackson, 2010; Morrison et al., 2013; Sanders et al., 2007), parents’ relationships with health care providers (Yin et al., 2012), and parents’ ability to follow medication instructions (Bailey et al., 2009; Lokker et al., 2009; Moon et al., 1998; Rosman, Dorfman, Suglia, Humphrey, & Silverstein, 2012; Yin et al., 2010). Following a systematic review of the literature, Sanders et al. (2009) concluded that low health literacy among caregivers is associated with poor preventive care behaviors. Other researchers, however, have found no association between caregiver health literacy and the use of child health services. That lack of a link was the conclusion of Sanders et al. (2007) in their cross-sectional study of 290 caregiver-child dyads recruited from a pediatric emergency department. Two more recent studies set forth other findings. Whereas Morrison et al. (2013) stated there may be a relationship between low health literacy and increased utilization of the emergency department by children, an intervention study conducted by Herman and Jackson (2010) found there was a reduction in both emergency room and doctor visits during as well as after a health literacy intervention was used with parents whose children were enrolled in Head Start (a federal government program for low-income families). This finding suggests the need for additional research to clarify the connection between parental health literacy and utilization of health care services.

Past studies that have explored the relationship of parents' health literacy to their ability to adhere to medication-related instructions are likewise conflicting. Moon et al. (1998) did not find a connection between parental literacy (as measured by the REALM) and parents' understanding of medical information. Similarly, Rosman et al. (2012) used the REALM to assess caregiver health literacy and found that health literacy did not predict which families would fill their children's prescriptions following a visit to the pediatric emergency department. To the contrary, three different studies on parents' abilities to correctly administer medications to their children found low health literacy and numeracy skills to be a significant risk factor for medication-related errors (Bailey et al., 2009; Lokker et al., 2009; Yin et al., 2010).

Hospitalization of a Child

A Child's Experience of Hospitalization

Hospitalization is widely understood to be a stressful experience for children of all ages (Ball et al., 2012; Melnyk, 2000). The specific stressors associated with a hospital stay vary based on the child’s developmental stage. Four stressors have been identified that affect all hospitalized children regardless of age: “separation from parents, primary caregiver, or peers; loss of self-control, autonomy, and privacy; painful and/or invasive procedures; [and] fear of bodily injury and disfigurement” (Ball et al., 2012, p. 263). Recognizing a child’s concerns regarding a hospital stay enables nurses to better understand the child’s responses to these worries and provide appropriate nursing care (Ball et al., 2012).

Parental Needs During a Child’s Hospitalization

Children are not the only ones affected by hospitalization; a child’s hospital stay also significantly affects his or her parents (Ball et al., 2012; Hallstrom, Runesson, & Elander, 2002; Hopia, Tomlinson, Paavilainen, & Astedt-Kurki, 2005; Melnyk, 2000; Wray, Lee, Dearmun, & Franck, 2011). Hospitalization causes numerous sources of stress for parents, including anxiety and fear related to the ill child, family concerns, worry about missed work, and financial burdens associated with the hospital stay (Ball et al., 2012).

Published studies have utilized various methods to ascertain the needs of parents when they have a child who is hospitalized. In their StayClose study, Wray et al. (2011) employed mixed methods to explore parental anxiety, hospital-related stress, and parental coping. Data were collected at 3 time points: in the hospital soon after admission, at discharge, and 3 months post-discharge. Through this longitudinal pilot study, this research group confirmed findings from earlier studies, concluding that “parents experience substantial stress and anxiety when their child is hospitalised” (Wray et al., 2011, p. 172). A particularly noteworthy result of this study was that 38% of parents had borderline/clinical levels of anxiety that persisted 3 months after their child’s discharge from the hospital.

In their 2005 study, Hopia and colleagues interviewed 31 families to explore firsthand how nurses can help promote the health of the members of a family unit while one member is hospitalized. A grounded theory approach was used to analyze the data collected during the interviews. Researchers categorized nurses’ behaviors that promoted family health during a child’s hospitalization into five domains: “(1) reinforcing parenthood; (2) looking after the child’s welfare; (3) sharing the emotional burden; (4) support for everyday coping; and (5) creating a confidential care relationship” (Hopia et al., 2005, p. 216). Within each domain, there are suggested ways for nurses to intervene to support families during a hospital stay. For example, Hallstrom et al. (2002) used nonparticipant observations to determine parental needs during a child’s hospitalization. In their study, 24 children and their parents receiving care in a variety of hospital settings were observed for a cumulative total of 134 hours. Analysis of the data yielded nine themes—i.e., nine parental needs: the need for security, mediation of security for their child, communication, control, parental competency, fitting in, family, relief, and satisfaction of practical needs (Hallstrom et al., 2002, p. 144). Researchers asked two questions of parent participants as a means of confirming the conclusions drawn from their observations: “Which needs are important to you during your child’s hospitalization?” and “What do you do to get your needs satisfied?” (Hallstrom et al., 2002). Although these three studies—by Wray et al. (2011), Hopia et al. (2005), and Hallstrom et al. (2002)—utilized different research methods, their findings were similar.

All three studies also reinforce the fact that nurses play an instrumental role in the care of both children and their parents during a hospital stay.

Hospital Discharge

Readiness for Hospital Discharge

Although discharge occurs when the circumstances necessitating the hospital stay have been managed or resolved, preparation for discharge should begin as soon as a child is admitted to the hospital (Ball et al., 2012). Hospital discharge is an issue that affects persons of all ages who face hospitalization for a variety of reasons. Of particular relevance to this review of the literature, Weiss et al. (2008) developed the Readiness for Hospital Discharge Scale—Parent Form (RHDS) to assess parents' perceptions regarding a child's readiness for discharge. In the development of this instrument, the research team acknowledged the complexity of the issue of readiness for discharge. The decision to send a child home from the hospital encompasses much more than the child's physical status: "Discharge readiness assessment of the pediatric patient should extend beyond criteria for physiologic stability to consideration of the capacity, abilities, availability, and accessibility of family members and community support for posthospitalization care needs" (Weiss et al., 2008, p. 283). Items included in the parent version of the RHDS pertain to both the child and the parent, which supports the prior discussion regarding the dual impact of a hospitalization on both children and their parents. Other versions of the RHDS assessment have been designed for use with adult medical-surgical patients (Weiss et al., 2007) and postpartum mothers (Weiss & Lokken, 2009).

The RHDS—Parent Form has been used in two published studies, one involving parents of children with various diagnoses who were hospitalized at a children's medical center (Weiss et al., 2008) and another that included parents of children who received solid organ transplants (heart, kidney, or liver) at one of three major pediatric transplant centers (Lerret & Weiss, 2011). In the first study, the researchers set out to determine what predicted a parent's perception of being ready to take a child home from the hospital. The following variables were included in the study: parent, child, and hospitalization characteristics; parental readiness for hospital discharge; discharge teaching and care coordination by nurses; post-discharge coping difficulty; and utilization of post-discharge support and health services. In that study by Weiss et al., the only statistically significant predictor of a parent's readiness for hospital discharge was the nurse's delivery of discharge teaching, and this factor only partially explained parental readiness for discharge. Researchers acknowledged that "other parent, child, and hospitalization factors and disease-specific parent/patient needs not measured in this study may contribute more substantially to readiness for discharge and post-discharge outcomes than the delivery of discharge teaching" (Weiss et al., 2008, p. 292).

In the second published study that used the RHDS—Parent Form, Lerret and Weiss (2011) found that coordination of the child's care in the hospital affected readiness for discharge in this specialized patient population (children undergoing organ transplantation) and influenced post-discharge outcomes. Quality of discharge teaching also was measured in this study but was not found to be associated with the parent's readiness to take the child home from the hospital. In the discussion of study findings, the researchers asserted that patient education is an essential nursing responsibility as well as a determinant of the child's ability to thrive after discharge from the hospital (Lerret & Weiss, 2011).

Nurses' Role in Preparing Children and Parents for Discharge

When caring for a hospitalized child, nurses are challenged to provide holistic, family-centered care. Child and family education is a vital responsibility of pediatric nurses. Nurses incorporate teaching throughout the hospital stay to help prepare children and their families for discharge (Ball et al., 2012). The importance of educating patients and families is emphasized in the AHRQ's *Guide to Patient and Family Engagement*. In this document, the IDEAL Discharge Planning strategy, which is implemented at the time of hospital admission, is presented and can be used by nurses to guide preparation for patients' discharge (AHRQ, 2013).

Challenges During the Post-Hospital Transition

In recent years, hospital stays have become shorter than in the past. A shorter length of stay means nurses have less time to educate and prepare patients for discharge, and therefore more potential for coping difficulties and other problems after hospitalization (Braun, Baidusi, Alroy, & Azzam, 2009; Miller, Piacentine, & Weiss, 2008). In one study of adult patients, persons of low socioeconomic status were at a particularly high risk of experiencing difficulties related to the transition from hospital to home. Study participants admitted to having trouble adhering to discharge instructions and medication regimens, oftentimes due to financial constraints and other life demands (Kangovi et al., 2014). In the qualitative portion of a mixed methods study involving adult medical-surgical patients, Miller et al. (2008) found that the coping difficulties encountered during the first 3 weeks after hospitalization could be grouped into the following categories: specific stressors—i.e., pain, managing complications, work-related concerns; caring for self and managing the medical condition; family concerns; advice needed from family or friends; needing to call the MD, use emergency services, or be readmitted to the hospital; and what patients wished they had known.

Parents' Understanding of Discharge Information

Despite the fact that nurses teach parents and children throughout hospitalization and health care encounters, existing research shows that patients and families do not always understand the discharge instructions provided (Chappuy et al., 2012; Zavala & Shaffer, 2011). Researchers have conducted studies to determine if there are specific actions that can be taken during a hospital stay or visit to an emergency department to improve understanding of the information communicated at and before discharge (Braun et al., 2009; Chappuy et al., 2012; Keatinge, Stevenson, & Fitzgerald, 2009; Macy et al., 2011; Zavala & Shaffer, 2011). Based on existing research, strategies that appear to improve the discharge process include telephone follow-up with patients after discharge (Braun et al., 2009; Zavala & Shaffer, 2011), use of plain language rather than medical jargon when communicating with parents (Keatinge et al., 2009), provision of information in both written and verbal forms (Keatinge et al., 2009; Macy et al., 2011), adequate pain management for the child prior to instructing parents (Chappuy et al., 2012), and a nurse's repetition of the information communicated by the doctor prior to discharge (Chappuy et al., 2012).

At the site of the current study, the previously mentioned strategies known to make hospital discharge smoother are already in place to some extent. Nurses routinely call parents within several days of a child's discharge to ensure that the patient and parent were satisfied with all aspects of the hospital stay. At the time of discharge teaching, nurses give parents printed discharge instructions and a medication list. Pain assessment and pain management are quality improvement indicators monitored within this hospital system, and adequate pain management is a priority for every patient. Throughout the child's hospitalization, and again prior to discharge, both medical and nursing staff provide instructions to the patient's parents in an effort to prepare them to care for their child's health needs after leaving the hospital.

Health Literacy and Medications

Following a hospitalization, the discharge needs of each child are unique. Nevertheless, certain standard points are covered in all discharge teaching sessions, including plans for hospital follow-up, a phone number to call for questions that arise after discharge, medication and home care instructions, and signs and symptoms for which to monitor that are specific to the patient's condition (Ball et al., 2012). Several studies conducted to date indicate that parents commonly make errors when administering medications to their children. Parent participants for these studies were recruited from various clinic locations (Bailey et al., 2009; Lokker et al., 2009; Yin et al., 2011; Yin et al., 2010). In each of those studies, the health literacy of parents was assessed to determine whether parents' health literacy contributed to the ability to understand medication instructions and correctly administer prescribed dosages. In the studies, health literacy was measured using one of three instruments, each of which was discussed above: the REALM (Bailey et al., 2009), the S-TOFHLA (Lokker et al., 2009), or the NVS (Yin et al., 2011; Yin et al., 2010). In each study, researchers concluded that limited health literacy increased the likelihood of committing a medication error.

Yin et al. (2011) acknowledged that medication errors are also made by parents who have adequate health literacy. In their study, 299 parents were given one of two types of instructions (text plus pictogram or text only); 22.2% to 30.0% of the participants in the adequate literacy group incorrectly dosed the medication (Yin et al., 2011). Based on those and similar findings, researchers have recommended various strategies to decrease parental medication errors. For example, Lokker et al. (2009) proposed revising existing medication labels to enhance parental understanding of instructions on over-the-counter cough and cold medications. Similarly, Bailey et al. (2009) suggested that medication instructions should be standardized and written concisely. In their study, Yin et al. (2010) found the incidence of medication errors varied by dosing instrument (cup, dropper, dosing spoon, or oral syringe); thus, these researchers asserted, one way to reduce mistakes is by including instructions on how to accurately use the appropriate dosing device. In a subsequent study by several members of that research team, the use of dosing diagrams coupled with written medication instructions was found to decrease the likelihood of medication errors, especially among parents with low health literacy (Yin et al., 2011).

Utilization of Health Services after Hospitalization

Little has been published on the utilization of health services following a child’s hospitalization. There have been articles written on the utilization of the emergency department; specifically, researchers have sought to identify factors that predict use of the emergency department (Halfon, Newacheck, Wood, & St. Peter, 1996; Johnson & Rimsza, 2004). Receiving care in an emergency department is known to be costly and is not always the most appropriate source of care, such as for regular pediatric sick visits. In one study, the following demographic factors were associated with increased use of the emergency department for the care of basic illnesses in children: being Black, single-parent families, mothers with less than a high school education, poorer families, and families living in an urban setting (Halfon et al., 1996). In a 2004 study, Johnson and Rimsza concluded that access to pediatric care decreased the likelihood of emergency department use. Prior to a child's discharge, the nurse should determine where the child will receive follow-up care related to the hospital stay (if and when it is needed), as existing research has shown families do not always understand the instructions provided (Chappuy et al., 2012; Zavala & Shaffer, 2011).

Limitations of Existing Research

To date, few published studies have specifically addressed readiness for hospital discharge. A review of the existing research returned two studies that targeted parents of hospitalized children (Lerret & Weiss, 2011; Weiss et al., 2008), one that involved adult medical-surgical patients (Weiss et al., 2007) and one that addressed postpartum mothers' perceptions of preparedness to leave the hospital (Weiss & Lokken, 2009). Assessment of health literacy was not included in any of these past studies.

Hospital discharge is recognized to be a complex process that requires significant preparation to ensure optimal patient outcomes (Foust, Vuckovic, & Henriquez, 2012; Lerret, 2009; Weiss et al., 2008). Although few existing studies have explored the transition from hospital to home among pediatric patients (Lerret & Weiss, 2011), a comprehensive review of the literature on health literacy and hospital discharge indicates that an assessment of parents' health literacy—including their comprehension of discharge teaching—is essential prior to the child being sent home.

A review of the two studies that utilized the RHDS and specifically addressed parental readiness for discharge supports the need for additional research in this area

(Lerret & Weiss, 2011; Weiss et al., 2008). The first study included parents of children who were admitted for varying diagnoses to a children's medical center in the Midwestern United States. The study sample lacked diversity: 124 of the 135 parents (91.9%) were women, a majority of participants (71%) were married, and 71% were White. However, researchers commented that the demographics of the sample were characteristic of that geographic area (Weiss et al., 2008). The second study—by Lerret and Weiss (2011)—included 37 parent participants who were noted to be the primary caregiver of a child who had received a solid organ transplant (heart, kidney, or liver) at one of three pediatric transplant centers. Similar to the sample in the Weiss et al. 2008 study, a majority of the participants were female (73%), married (75.7%), and Caucasian (67.6%). All parents who met the inclusion criteria were invited to take part. Seven parents declined participation (Lerret & Weiss, 2011). The descriptions of the samples in these two studies support the need for additional research that includes greater diversity among participants.

In Weiss et al.'s 2008 study of parents of general pediatric patients, 123 of the 135 parents (91%) who enrolled in the study completed data collection on the day of hospital discharge, and 119 (88%) participated in the telephone interview conducted 3 weeks after discharge. Though the authors did not directly state this, there was no apparent attrition of the sample in the study of parents of pediatric transplant recipients, as post-discharge data were documented on all 37 parent participants (Lerret & Weiss, 2011).

In their study of parents of hospitalized children, Weiss et al. (2008) had an adequate sample size to perform regression analyses. However, in the models tested, the only significant predictors of readiness for discharge were the number of other children in the home and the quality of discharge teaching. The Quality of Discharge Teaching Scale (QDTS) was used as a means of evaluating the instruction provided to parents. In a discussion of study findings, the researchers commented: “The study model explained a small portion of the variance in parental readiness for discharge and postdischarge coping. Additional variables should be tested with the significant variables identified in this study to increase the explanatory power” (Weiss et al., 2008, p. 294). Another possible explanation for the lack of significant findings may relate to the fact that parents participating in this study represented children who were hospitalized for a myriad of reasons. Although including parents of children admitted for diverse reasons helped with recruitment of a sufficient sample, the range of children represented by the parent respondents “may have masked transition differences and issues arising from specific disease, diagnoses, or procedure situations” (Weiss et al., 2008, p. 294).

While Lerret and Weiss (2011) acknowledged that the small sample size in their study involving parents of pediatric transplant recipients affected the statistical analyses performed, this research involved a very specific population—a limitation that may have affected recruitment. Strengths of their work, on the other hand, included enrolling participants from multiple transplant centers and producing findings that add meaningfully to the knowledge about readiness for hospital discharge in the pediatric solid organ transplant population.

Although past research on readiness for discharge among those hospitalized as inpatients does not incorporate an evaluation of participants’ health literacy, two published studies—conducted in the emergency department setting—have addressed comprehension of discharge instructions (Chappuy et al., 2012; Zavala & Shaffer, 2011). Interestingly, even those two studies, one involving parents of children who were seen in a pediatric emergency department and one that included adult patients, did not incorporate measurement of health literacy (Chappuy et al., 2012; Zavala & Shaffer, 2011). Although these studies did not contain an assessment of participants' health literacy, two systematic reviews have been conducted on literature that addresses health literacy as a topic, and these studies must be considered when evaluating understanding of discharge instructions provided in the emergency department (Alberti & Nannini, 2013; Herndon et al., 2011).

Conclusion

A review of existing research indicates that more work is needed in the area of parental health literacy. To date, most health literacy studies have targeted adult patients. Additionally, based on current findings, the literature lacks agreement on the relationship between the health literacy of parents and the health outcomes of their child (or children). The nature of this association must be clarified so that further intervention research addressing parental health literacy can be conducted—and, ultimately, contribute to improved clinical practices and child health outcomes. In prior studies on readiness for hospital discharge, researchers have concluded that there may be other predictors of readiness for discharge that affect outcomes following a hospitalization. This review of the literature on health literacy indicates that parental health literacy is likely a contributing factor to parents' perception of readiness for hospital discharge as well as post-hospitalization outcomes. This study is the first to examine the relationship between caregiver health literacy and readiness for hospital discharge, caregivers' post-discharge coping, and utilization of health services after hospital discharge.

Conceptual/Theoretical Framework

Meleis's transitions theory, a middle-range theory, was selected as the basis for this research study. Findings from five separate research studies involving various populations were assimilated in the establishment of this theory (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000). First, however, a definition of transition and an understanding of the transitions process and transitions theory are in order.

The concept of transition is fundamental in nursing, and there are numerous ways to explain the aspects of a transition process. Meleis (2010), in her book *Transitions Theory: Middle Range and Situation Specific Theories in Nursing Research and Practice*, proposed the following definition of a "transition": "a passage from one fairly stable state, to another fairly stable state, and it is a process triggered by change" (p. 11). Transitions theory has been utilized as the theoretical framework for prior studies on readiness for hospital discharge (Weiss & Lokken, 2009; Weiss et al., 2007; Weiss et al., 2008). Transitions theory consists of six main components: types and patterns of transitions, properties of transition experiences, transition conditions (facilitators and inhibitors), process indicators, outcome indicators, and nursing therapeutics (see Figure 1; Meleis et al., 2000).

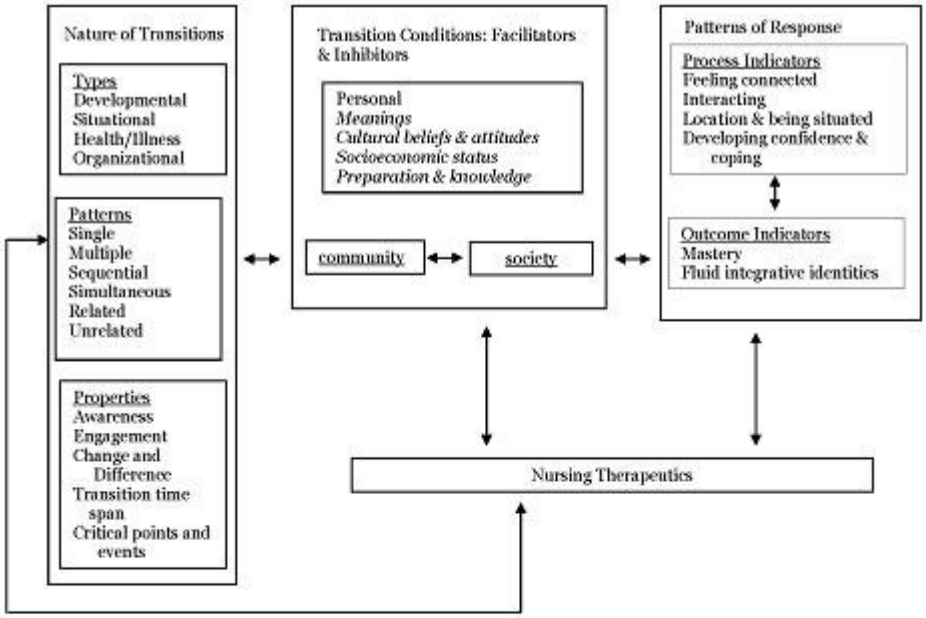

Figure 1. Meleis' transitions theory.

In the current study, caregiver health literacy was considered a transition condition—something not done in previous research. Transition conditions are "personal and environmental conditions that facilitate or hinder progress toward achieving a healthy transition" (Meleis et al., 2000, p. 21). Specifically, health literacy was considered as one element of preparation and knowledge listed as a transition condition. It was hypothesized that adequate caregiver health literacy would facilitate the transition process when a child is discharged from the hospital, and that those caregivers measured to have adequate health literacy would experience fewer coping difficulties and utilize health services appropriately during the post-hospital period. Conversely, it was hypothesized that caregivers with low health literacy would be less prepared for hospital discharge, have more difficulty with the transition from hospital to home, and experience more coping difficulties following a child's hospitalization.

Research Aims

Aim 1: Investigate the relationship between caregiver health literacy and the caregiver’s perception of readiness for hospital discharge.

Aim 2: Investigate the relationship between caregiver health literacy and caregivers’ post-discharge coping.

Aim 3: Investigate the relationship between caregiver health literacy and utilization of health services for the child after hospital discharge.

CHAPTER III: METHODS

Research Design

A descriptive correlational research design was used to explore the relationship between caregiver health literacy, caregivers' perceptions of readiness for hospital discharge, caregivers' post-discharge coping, and utilization of health services for the child following discharge. After gaining the approval of the University of Virginia's Institutional Review Board (IRB) for Social and Behavioral Sciences (the institution with which the principal investigator is associated), and from the Centra IRB, parents (or other primary caregivers) of children admitted to the pediatrics unit at the study setting (described in more detail below) were invited to participate in this study.

Descriptive correlational studies seek to determine relationships between variables. This type of research falls under the broader category of non-experimental research. Although results from this type of study can be explained in various ways, it is essential to describe the relationships between and among these variables (caregiver health literacy, readiness for hospital discharge, post-discharge coping, and utilization of health services after hospital discharge) before an experimental study can be considered (Polit & Beck, 2008).

Description of Research Setting

Description of the Site and Surrounding Geography

The study was conducted in Lynchburg, Virginia, on the pediatrics unit of Centra Lynchburg General Hospital. The city of Lynchburg is situated near the geographic center of the state of Virginia and covers approximately 50 square miles. Lynchburg is

180 miles southwest of Washington, D.C. The city is adjacent to the eastern portion of the Blue Ridge Mountains (City of Lynchburg, Virginia, website, n.d.).

Description of the Population

According to the 2010 U.S. Census, the most recent information available, the population of Lynchburg is 75,568. In terms of race, the population is made up of 64.4% White, 29.3% Black or African American, 3.0% Hispanic or Latino, 2.5% Asian, 0.3% American Indian and Alaska Native, <0.1% Native Hawaiian and Other Pacific Islander, and 2.2% a mix of two or more races. Persons 65 years and older comprise 14.0% of the population, while 19.6% are under the age of 18. Of those 25 and older, 87.3% have a high school education or more, and 32.3% have a bachelor’s degree or higher. The median household income of the city’s total population is $39,391, and 25.0% of the population lives below the poverty level (U.S. Census Bureau, March 27, 2014).

Centra

Centra is a regional, nonprofit health care system that includes four hospitals, all in Virginia: Lynchburg General Hospital and Virginia Baptist Hospital in Lynchburg, Bedford Memorial Hospital in Bedford, and Southside Community Hospital in Farmville. Employees of Centra provide care to more than 500,000 people in a total of 38 locations (including numerous outpatient facilities as well as the four hospitals) throughout Central and Southside Virginia. The pediatrics unit where the study was conducted is located at Lynchburg General Hospital, which is a Level II Trauma Center with 358 licensed beds (Centra Health website, 2009–2016).

Centra recognizes the importance of health literacy and the teach-back method (previously discussed) to prepare patients and families for discharge. All nurses are required to complete an educational module on these topics. It is then mandatory for the nurses to use and document the teach-back method during patient/family education sessions.

The Pediatrics Unit

The pediatrics unit at Lynchburg General Hospital is an 11-bed medical-surgical pediatric unit staffed by pediatric hospitalists and registered nurses. A total of 1,258 patients were admitted to the unit during the 2014 calendar year, and there were 895 admissions in 2015. During the months of study participant recruitment (November 2014 through March 2015), 471 patients were admitted to the unit. Patients are admitted to the pediatrics unit with a variety of medical and surgical diagnoses, and the average daily census of the unit was 3.5 patients in 2014 and 2.5 patients in 2015 (C. Goad, personal communication, January 18, 2016).

The pediatrics unit implemented the teach-back approach in May 2014 in an effort to better prepare patients and families for discharge. Teach-back data are collected routinely on pediatric patients admitted for asthma. Because of this preexisting method for preparing select patients and their families for discharge and the naturalistic design of this research, study findings should be interpreted with an understanding that there was no manipulation of the environment by the researcher (Burns & Grove, 2009).

Sample

Protection of Human Subjects

This study was submitted for IRB approval at both the University of Virginia and Centra. After obtaining these approvals, the principal investigator (PI) approached parents or caregivers of children admitted to the pediatrics unit at the study site in

Lynchburg and asked them about participating in this study, unless a physician indicated they should not be considered. In the patient's private hospital room, the PI verbally explained the research study and study procedures to the parent or caregiver, and answered questions raised by the prospective participants. The PI went through the consent process with parents who agreed to be part of the study. The PI offered to read through the consent form with the parent participant if he or she wished, as this would help offset difficulties caused by participants' low literacy levels, if present—a concern at the center of this study. If they desired, parent participants were allowed to read and provide consent on their own, without the PI's assistance. The PI was available to answer questions about the study or study procedures raised during the consent process.

Potential risks of the study were explained to prospective participants. This study did not present more than minimal risk to participants. The primary risk was that of disclosure of identifiable information. Study identification numbers were used on all study instruments as a means to protect participant confidentiality. There were no risks to the children of the parent participants, as only the parent-caregivers provided data for this study.

Sample Size

The target sample size for the study was 120 parents and/or primary caregivers. To account for a possible attrition of 20% between the initial data collection in the hospital and the last time point for data collection (3 weeks after discharge), 150 parents were targeted for recruitment. A sample of 120 was determined to be sufficient for the planned analyses (bivariate correlation and multiple regression). The power for the correlations was computed using nQuery, a statistical analysis program. Cohen (1992) described a bivariate correlation of .3 as “medium-sized.” A two-sided Fisher’s z test at significance level α = .05 of the null hypothesis that Pearson correlation coefficient ρ = 0.000, will have 91% power to detect a medium-sized ρ of 0.300 when the sample size is 120. The multiple regression models will have 12 predictors. According to Harrell (2001), a fitted multiple regression model is likely to be reliable when there are at least 10 cases per predictor in the model. A sample size of 120 should be sufficient for models with 12 predictors.

For the third research aim, it was expected that chi-square or logistic regression could be used to analyze data relative to caregiver health literacy and the utilization of health services for the child after hospital discharge. However, further investigation revealed that there may not be sufficient power for this aim, given the sample size required for the other statistical analyses as well as the number of participants that can be recruited within a reasonable amount of time. This aim was still included for exploratory purposes.

Criteria for Sample Selection

Parents and other legal guardians of children who were admitted to the pediatrics unit were approached regarding participation in this study. To be eligible, the participant had to speak English and have a working telephone number where he or she could be reached after hospital discharge. Non-English speaking parents/legal guardians were excluded because the study instruments have not been translated into other languages. Due to the potential changes in guardianship or living arrangements following hospital discharge, foster parents were not approached for study participation.

Procedure

All participants were required to sign a consent form to take part in this study. After giving consent, participants received an envelope with the initial two study instruments: the Demographic Information Form and the Self-Reported Health Literacy Measure. After completing these two forms, the participants returned them to the PI in the envelope provided. The Readiness for Hospital Discharge Scale—Parent Form was developed to be administered on the day of hospital discharge, within 4 hours of the anticipated discharge time. Thus, this study instrument was distributed and completed at the hospital, as close to the time of discharge as possible. Due to the typically short length of stay on the pediatrics unit, some participants received all three study instruments at the same time, shortly before the child's discharge.

The Post-Discharge Coping Difficulty Scale was used to conduct follow-up phone calls with study participants 3 weeks after hospital discharge. While in the hospital with their child, study participants provided a telephone number where they could be contacted after discharge. Three weeks from the hospital discharge date, the first call was made to study participants at the phone number provided so they could complete the final portion of the study. If there was no answer the first time, repeated attempts to contact the parent were made daily for the next 7 days (for a total of eight possible calls). If parents could not be reached after 1 week, they were considered lost to follow-up. Messages (including a call-back number) were left when there was no answer, and caregivers sometimes returned the PI's call to complete the follow-up data collection.

Data Collection Methods

Techniques

With the exception of the Demographic Information Form, the instruments used in this study all had established reliability and validity. All study instruments appear in Appendices A–D. The Demographic Information Form was developed by the PI specifically for this study based on the aforementioned research on readiness for hospital discharge and a review of the health literacy literature.

Instruments

Demographic Information Form. This instrument was developed by the PI and is made up of items relating to the parent, the child, and the hospitalization. The form consists of 12 items and can be completed in approximately 2 minutes. The Flesch-Kincaid reading level of this form, the most widely used measure of readability, is grade level 3.6. The form collects the parent’s (or legal guardian’s) age, gender, race, marital status, highest level of education completed, and household income. Additionally, the form asks for the child’s age, reason for the child’s hospitalization, number of days hospitalized, and whether or not the child has been in the hospital for the same reason in the past. The form also obtains the total number of adults and children residing in the home as well as the location where the child would receive post-discharge health care. Information from this form was used in the statistical tests performed.

Self-Reported Health Literacy Measure. This instrument consists of three questions and has been shown to be an effective tool to estimate health literacy in a variety of populations (Sarkar et al., 2010). The questions that comprise this measure are: (1) “How confident are you filling out medical forms by yourself?”; (2) “How often do you have problems learning about your medical condition because of difficulty understanding written information?”; and (3) “How often do you have someone like a family member, friend, hospital or clinic worker, or caregiver help you read hospital materials?” A Likert scale (1–5) is used to score each question. Scores on the three questions are totaled to determine the respondent’s self-reported health literacy. Overall scores on this instrument range from 3 to 15, with higher scores indicating lower levels of health literacy (Sarkar et al., 2010). In a study validating how well these questions are able to delineate persons who have adequate, marginal, or inadequate levels of health literacy, “a cut point of 9, corresponding to answers of ‘sometimes/somewhat’ on all three questions, appeared to maximize both sensitivity and specificity for English and Spanish speakers” (Sarkar et al., 2010, p. 267).

Readiness for Hospital Discharge Scale—Parent Form. The RHDS was originally developed and tested across three different populations: postpartum new mothers, adult medical-surgical patients, and parents of hospitalized children. Reliability and validity were established using data from these respondents collectively. The RHDS (in its originally developed format) is made up of 21 shared items that can be used in all three of these groups. This instrument was developed to be administered on the day of hospital discharge, within 4 hours of the anticipated time of discharge. With the exception of one question (Question 1, parts a and b), each item on the scale uses an 11-point rating scale (0–10). Wording is included at both ends of the scale to help guide respondents. Completion of this measure takes less than 5 minutes. While the Flesch-Kincaid reading level of this instrument is grade level 8.1, modifications to the design and layout were made on the measure for use in this study, so as to accommodate participants with low health literacy. Population-specific modifications were made to create the version of the RHDS used in this study. This adapted version consists of 32 items, 29 of which are scored. The scored items are divided into five categories or subscales: Personal Status—Parent (eight items), Personal Status—Child (five items), Knowledge (nine items), Coping Ability (three items), and Expected Support (four items). The instrument includes one dichotomous question not part of the scoring (Questions 1a and 1b). Additionally, Question 6b, which asks the parent to rate the child's level of stress, was not included in the scoring for this study because the study development team felt the question was not appropriate for children of all ages (M. Weiss, personal communication, May 5, 2014). After reverse-coding three items (3a, 3b, and 6a), a total score is obtained by summing the scores for all five subscales. The maximum score on the RHDS is 290; higher scores indicate greater readiness for discharge. The Cronbach's alpha of the RHDS (parent version) is .85 (Weiss & Piacentine, 2006).

Post-Discharge Coping Difficulty Scale (PDCDS). The PDCDS was administered orally during the follow-up telephone call, and the responses were recorded by the PI. Eleven of the 12 items on the PDCDS are included in the total score (Question 6b is omitted). The 11 scored items use the same 11-point scale (0–10) as the RHDS and can be used to gauge a parent's experiences of caring for a child after hospital discharge. Four items must be reverse-coded, and then the scores on the 11 items are summed to create a total score. Total PDCDS scores range from 0 to 110, with higher scores representing greater difficulty with coping (Weiss et al., 2008). Psychometric testing of the PDCDS yielded a Cronbach's alpha reliability of .82 (Weiss & Piacentine, 2006).

Post-Discharge Utilization of Healthcare Resources Measure. Like the PDCDS, this tool was administered orally during the follow-up telephone call, and responses were recorded by the PI. Consisting of nine items, the Post-Discharge Utilization of Healthcare Resources instrument seeks to determine what type(s) of assistance the parent needed in terms of caring for the child after hospital discharge. Specifically, parents are asked to self-report whether or not they made calls to family or friends for advice or support, calls or visits to the child's doctor, calls to the hospital, visits to an urgent care or emergency department, and/or their child was readmitted to the hospital. Parents are asked to respond either yes or no to six dichotomous format questions. The form includes three additional questions—two open-ended and one with categorical response options—that seek to determine parents' perceptions of the amount of discharge teaching received and the effect of that instruction on their post-hospital experiences (Weiss et al., 2008). The PI added one other question to the end of this instrument to determine if the child's post-hospital health care was obtained where the parent previously responded it would be. Three response options were listed—pediatrician's office, family doctor's office, and Johnson Health Center (a non-profit clinic that provides care at reduced fees to uninsured and underinsured patients in Lynchburg and several surrounding counties)—along with the opportunity to provide a different answer if appropriate.

Statistical Analysis

All statistical analyses were performed using SPSS Statistics 23 for Windows. Descriptive statistics were used to describe the study sample. Following is a discussion of the statistical analysis plan by study aim.

Aim 1. The first research aim investigated the relationship between caregiver health literacy and the caregiver's perception of readiness for hospital discharge. Bivariate correlation was used to estimate the strength and direction of the association between these two variables, and to test whether the association was significantly different from zero. Health literacy of parents was measured using the Self-Reported Health Literacy Measure, and readiness for hospital discharge was assessed using the Readiness for Hospital Discharge Scale—Parent Form (RHDS).

Bivariate correlation was followed by multiple regression to see if the relationship held up when other characteristics were taken into account. In the regression model, the dependent variable was readiness for discharge (as measured by the RHDS), and the predictor of interest was caregivers' health literacy (Self-Reported Health Literacy Measure). In addition to caregiver health literacy, the following demographic variables were included in the model: caregiver's age, gender, race (White/All other races), marital status (married/not married), education level (high school graduate or less/some college or more), total number of adults residing in the household, number of children in the home, household income ($\leq$ \$39,999/$\geq$ \$40,000), patient's age, number of days in the hospital, previous hospitalization(s) for the same reason (yes/no).

Aim 2. The second research aim was to discover whether there is an association between caregiver health literacy and caregivers' ability to cope after a child is discharged from the hospital. Bivariate correlation was used to assess this relationship, as no prior studies are known to have investigated these two concepts together. As with Aim 1, caregiver health literacy was measured using the Self-Reported Health Literacy Measure. Post-discharge coping was evaluated using the Post-Discharge Coping

Difficulty Scale (PDCDS). Bivariate correlation was followed by multiple regression to see if the relationship held up when other characteristics were taken into account. In the regression model, the dependent variable was parents' post-discharge coping and the predictor of interest was caregivers' health literacy. In addition, select demographic variables—the same ones described above for Aim 1—were entered into the regression model.

Aim 3. The third research question assessed the relationship between caregivers' health literacy and their utilization of health services for their child after the child's discharge from the hospital. As with the previous two aims, caregiver health literacy was measured using the Self-Reported Health Literacy Measure. Utilization of health services was assessed using the Post-Discharge Utilization of Healthcare Resources tool, which is typically administered alongside the PDCDS. It was expected that chi-square or logistic regression could be used to analyze this data. However, further investigation led to a concern that there might be insufficient power to carry out these analyses. In the end, this aim was included for exploratory purposes only.

Data gathered with the Post-Discharge Utilization of Healthcare Resources instrument gave rise to an important question of interest to this study: Does caregivers' health literacy affect the likelihood of seeking care for their children in the emergency department (versus a routine visit with a health care provider)? To answer this question, health literacy was dichotomized as either low or adequate, a categorization guided by prior research that validated this tool. Respondents received a score ranging from 3 to 15, with a higher score indicating a lower level of health literacy. Previous research involving this tool recommended a cut-off score of 9 when evaluating the data (Sarkar et al., 2010).

Thus, caregivers who scored 3–8 were categorized as having adequate health literacy, while those who scored 9–15 were labeled as having low health literacy.

CHAPTER IV: RESULTS

Demographics of the Study Sample

A total of 123 people were recruited between the months of November 2014 and March 2015 from the pediatrics unit at Centra Lynchburg General Hospital to participate in the study. All 123 recruits who gave signed consent to take part in the study completed the in-hospital data collection. Of these, 87 responded to the follow-up phone call conducted a few weeks after the child's discharge from the hospital. One person did not finish the follow-up call, resulting in data from 86 caregivers for many of the analyses involving follow-up data. This number is equivalent to a study completion rate of 69.9%. The number of days from the child's discharge to the follow-up telephone call ranged from 20 to 78, with a mean of 39.8 days.

Participants in this study were primarily female, and the majority of the caregivers were the mother of the hospitalized child. These demographics were not surprising, as the mother typically remains with the child throughout the hospitalization on the unit where the study was conducted. Though there was little variation in the gender and relationship to the child among study participants, the ages of caregivers ranged significantly, from 17 to 69 years old. The difference in caregivers' ages may have affected the study findings presented in this chapter. With respect to race, the majority of caregivers in the study were White; Blacks represented the second-largest group of participants. In terms of educational background, two-thirds of those who took part in the study had completed some college or less. Having less than a high school education has been identified as a risk factor for low health literacy (Morrison et al., 2013). Low socioeconomic status has also been associated with low health literacy (Morrison et al., 2013). Results of this health literacy study may have been influenced by the fact that a majority of the caregivers had less than a college education, and more than half of the participants reported an annual household income of $39,999 or less.

The average age of the hospitalized children was 3.81 years, with children ranging from newborn to 17 years of age. The mean length of stay for the children's hospitalization was 1.77 days. Of the children associated with the 123 study participants, 20 (16.3%) had been hospitalized previously for the same diagnosis, while 103 (83.7%) had not (see Table 1).

Table 1

Sample Characteristics (*N* = 123)[a]

Characteristic	*M* (SD)	*n*	%
Caregiver, child, and hospitalization characteristics			
Age of caregiver (years)	31.55 (9.36)		
Age of child (years)	3.81 (4.65)		
Length of hospital stay (days)	1.77 (0.99)		
Caregivers' scores on study instruments			
Self-Reported Health Literacy Measure (score range: 3–15)	5.42 (2.02)		
Readiness for Hospital Discharge Scale (mean score range: 0–10)	8.73 (.78)		
Post-Discharge Coping Difficulty Scale (mean score range: 0–10)	0.91 (.79)		
Demographic Characteristics			
Gender of caregiver			
Female		113	91.9
Male		10	8.1
Race of caregiver			
White		87	70.7
Black/African American		27	22.0
Two or more races		5	4.1
American Indian/Alaska Native		2	1.6
Asian		1	0.8
Hispanic/Latino		1	0.8

Table 1

Sample Characteristics (*N* = 123)[a]

Characteristic	*M* (SD)	*n*	%
Marital status of caregiver			
Married		61	49.6
Never married		46	37.4
Divorced		8	6.5
Separated		5	4.1
Widowed		2	1.6
Total household income per year			
< $20,000		32	26
$20,000–$39,999		37	30.1
$40,000–$59,999		19	15.4
≥ $60,000		28	22.8
Education of caregiver			
Less than high school		11	8.9
High school graduate		36	29.3
Some college		34	27.6
Associate’s degree		8	6.5
Bachelor’s degree		20	16.3
Master’s degree		9	7.3
Professional school degree		3	2.4
Doctorate degree		2	1.6
Previous admission of child for same diagnosis			
Yes		20	16.3
No		103	83.7
Post-discharge health care location[b]			
Pediatrician		58	45.3
Family Doctor		37	28.9
Johnson Health Center		27	21.1
Other		6	4.7
Caregiver health literacy			
Adequate		113	91.9
Low		10	8.1

[a] *N < 123 for some analyses due to missing data.*

[b] *N > 123 as some expected to receive post-discharge care from more than one provider.*

Given that health literacy was the central focus of this research, the study sample was also examined based on caregivers’ health literacy levels (ranked as either adequate or low; see Table 2). As explained at the end of Chapter III, the Self-Reported Health Literacy Measure scores were dichotomized following Sarkar et al. (2010); those with scores of 3–8 were classified as having adequate health literacy, and those who scored 9–15 were categorized as having low health literacy. Independent-samples *t*-tests were performed to compare caregivers of adequate versus low health literacy with respect to mean caregiver age, mean age of the child, and length of hospital stay. A statistically significant difference between the two groups was found for both the mean caregiver's age ($p = .042$) and the mean child's age ($p = .014$). The mean caregiver age in the adequate health literacy group ($M = 31.04$, *SD* 8.84) was significantly lower than the mean age of caregivers in the low health literacy group ($M = 37.30$, *SD* 13.19). The mean age of the children of caregivers in the adequate health literacy group ($M = 3.50$, *SD* 4.30) also was significantly lower than the mean age of the children of caregivers in the low health literacy group ($M = 7.24$, *SD* 6.94). Chi-square tests were performed to determine if there were other differences between the adequate and low health literacy groups, with respect to the categorical demographic variables. A significant interaction was found in the caregiver's level of education ($\chi^2(8) = 28.96$, $p = .000$); caregivers in the adequate health literacy group had a higher education level than those in the low health literacy group.

As stated earlier, findings from this study should be interpreted in light of the teach-back approach to discharge teaching, which is used with patients diagnosed with asthma in the pediatrics unit where the study was conducted.

Table 2

Sample Characteristics by Caregiver Health Literacy (*N* = 123[a])

Characteristic	*Mean* (SD)		*p*
	Adequate HL (*n* = 113, 91.9%)	Low HL (*n* = 10, 8.1%)	(*t*-test)
Age of caregiver (years)	31.04 (8.84)	37.30 (13.19)	.042
Age of child (years)	3.50 (4.30)	7.24 (6.94)	.014
Length of hospital stay (days)	1.77 (0.98)	1.80 (1.14)	.927
Gender of caregiver			.152
Female	105 (92.9)	8 (7.1)	
Male	8 (80)	2 (20)	
Race of caregiver			.763
White	81 (71.7)	6 (60)	
Black/African American	23 (20.4)	4 (40)	
Two or more races	5 (4.4)	0	
American Indian/Alaska Native	2 (1.8)	0	
Asian	1 (0.9)	0	
Hispanic/Latino	1 (0.9)	0 (0)	
Marital status of caregiver			.294
Married	58 (51.8)	3 (30)	
Never married	41 (36.6)	5 (50)	
Divorced	6 (5.4)	2 (20)	
Separated	5 (4.5)	0	
Widowed	2 (1.8)	0	
Total household income per year			.439
< $20,000	28 (26.4)	4 (40)	
$20,000–$39,999	33 (31.1)	4 (40)	
$40,000–$59,999	19 (17.9)	0	
≥ $60,000	26 (24.5)	2 (20)	
Education of caregiver			.000
Less than high school	6 (5.3)	5 (50)	
High school graduate	34 (30.1)	2 (20)	
Some college	31 (27.4)	3 (30)	
Associate’s degree	8 (7.1)	0	
Bachelor’s degree	20 (17.7)	0	
Master’s degree	9 (8)	0	
Professional school degree	3 (2.7)	0	
Doctorate degree	2 (1.8)	0	

Table 2

Sample Characteristics by Caregiver Health Literacy (*N* = 123[a])

Characteristic	*Mean* (SD) Adequate HL (*n* = 113, 91.9%)	*Mean* (SD) Low HL (*n* = 10, 8.1%)	*p* (*t*-test)
Previous admission of child for same diagnosis			.738
Yes	18 (15.9)	2 (20)	
No	95 (84.1)	8 (80)	
Post-discharge health care location[b]			
Pediatrician	54 (48.2)	4 (40)	.618
Family doctor	32 (28.6)	5 (50)	.158
Johnson Health Center	25 (22.3)	2 (20)	.865
Other	6 (5.4)	0	.453

Note. HL = Health literacy.

[a] *N < 123 for some analyses due to missing data.*

[b] *N > 123 as some will receive post-discharge care from more than one provider.*

Aim 1 Results

The first aim was to investigate the relationship between caregiver health literacy and the caregiver's perception of readiness for hospital discharge. The Pearson correlation between the Self-Reported Health Literacy Measure score and the Readiness for Hospital Discharge Scale score was -.025 (*p* = .399). Higher scores on the Self-Reported Health Literacy instrument indicate lower health literacy, and higher scores on the Readiness for Hospital Discharge Scale (RHDS) indicate greater readiness for discharge. The negative correlation between these two measures signifies that, as health literacy scores increased (i.e. lower health literacy), readiness for discharge also decreased (less ready for discharge).

To investigate this relationship in the context of other possible predictors, a linear regression was executed. The relationships between readiness for hospital discharge and each of the following 11 predictors were tested: health literacy, income (≤ \$39,999/ ≥ \$40,000), race (White/All other races), marital status (married/not married), education (high school graduate or less/some college or more), caregiver’s age, total number of adults in the household, number of children in the home, child’s age, number of days hospitalized, and whether or not the child had a prior hospital stay for the same diagnosis (yes/no). The caregiver’s health literacy level was not a significant predictor of readiness for discharge (p = .692). Only one other covariate, race, was a significant predictor (p = .013). The entire model, however, was not statistically significant (R^2= .149, p = .124).

All of the continuous variables in the regression, including the readiness for hospital discharge score, were skewed. Normalizing transformations were applied to all of the continuous variables, and the regression was rerun using the transformed variables. This model was significant (R^2 = .176, p = .049). However, even in the revised regression model, health literacy again had a very small, nonsignificant effect on readiness for hospital discharge (p = .484). Among the covariates, race again was significant (p = .005), and income also was significant (p = .046; see Table 3).

Table 3

Multiple Regression Results of Normalized RHDS Score

Variable	Estimate	SE	*p*
Caregiver health literacy (normalized)	.060	.085	.484
Caregiver age (normalized)	2.962	1.882	.119
No. adults in household (normalized)	-.035	.082	.675
No. children in household (normalized)	.095	.066	.154
Child's age (normalized)	.018	.042	.673
Days hospitalized (normalized)	.021	.045	.646
Total household income (dichotomous)	-.067	.033	.046*
Caregiver race (dichotomous)	-.090	.032	.005*
Caregiver marital status (dichotomous)	.055	.033	.094
Caregiver education (dichotomous)	-.016	.033	.634
Prior hospitalizations for same diagnosis (dichotomous)	.028	.038	.456

Note. RHDS = Readiness for Hospital Discharge Scale.
*Significance at .05 level.

The effects of health literacy and the two significant predictors (race and income) on readiness for discharge from the hospital were explored further by looking separately at the 29 scored items on the RHDS. The previously discussed dichotomized health literacy variable was used (adequate /low). The dichotomous variables for race (White/All other races) and income ($\leq$ \$39,999/ $\geq$ \$40,000) also were used. For each of the three dichotomized variables—health literacy, race, and income—the mean responses for every RHDS item were computed for the two levels of each variable. Items for which the mean value at the two levels differed by more than one point were noted, as this amount of difference could be used to establish clinical significance. Independent-samples *t*-tests were also run to determine if there were statistically significant differences between the groups with respect to the individual RHDS items. Response options on the RHDS questions range from 0 to 10, with higher scores signifying greater readiness for hospital discharge. Four of the questions on the RHDS were reverse-coded, per instructions from the instrument developer, to fit with the overall scoring of the measure.

Of the 29 scored items on the RHDS, two questions, caregiver stress and caregiver strength, showed at least a 1-point difference between the means for the two health literacy groups (adequate/low health literacy). For level of caregiver stress (as determined by a single item on the RHDS), the adequate health literacy group scored higher than the low health literacy group, indicating that caregivers with adequate health literacy reported less stress at the time of discharge than those with low health literacy. There was not a statistically significant difference in caregiver stress based on health literacy level ($p = .129$). In terms of caregiver strength (also determined by a single item on the RHDS), the low health literacy group scored higher than the adequate health literacy group, meaning that caregivers in the low health literacy group reported higher levels of strength at the time of discharge compared to those in the adequate health literacy group. The difference in caregiver strength between the two health literacy groups was not statistically significant ($p = .077$; see Figure 2). Based on t-tests, there was a significant difference between the caregivers in terms of physical readiness to go home from the hospital ($p = .039$). Caregivers in the adequate health literacy group reported being more physically ready for discharge ($M = 9.51$) than those in the low health literacy group ($M = 8.70$).

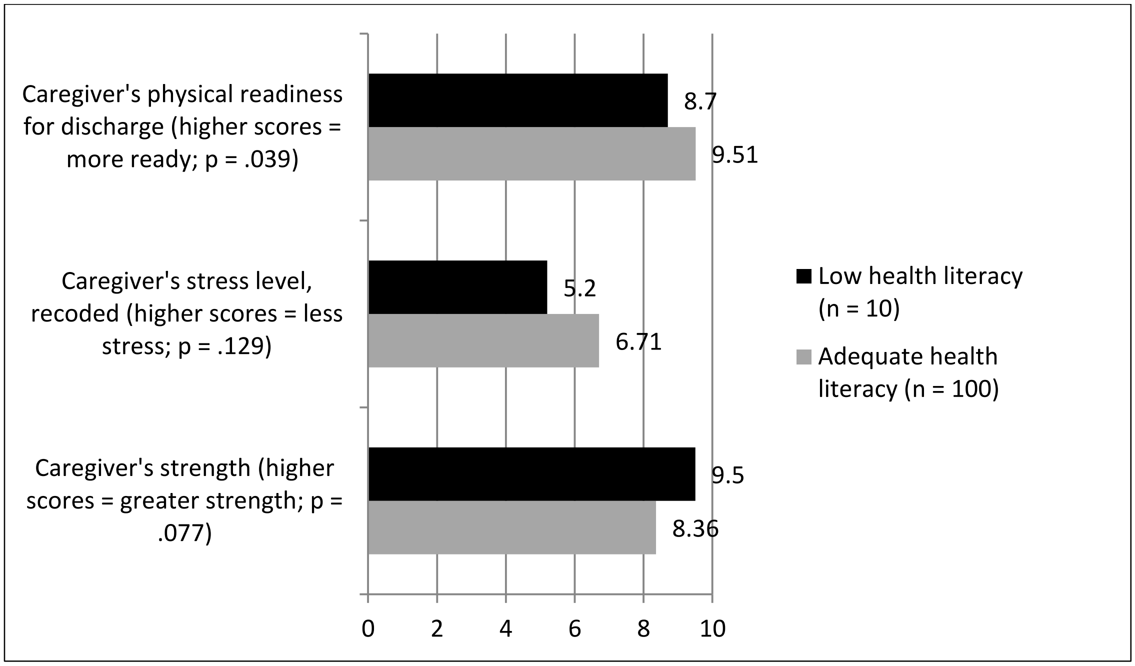

Figure 2. Readiness for Hospital Discharge Scale scores according to caregiver health literacy.

In regards to race, non-Whites had a higher mean score than Whites on 26 of the 29 RHDS items, and those differences were greater than 1 point on four items: caregiver stress, amount of help expected with child's condition after discharge, child's energy level, and caregiver's energy level. These higher mean scores suggest that minority caregivers were more ready for hospital discharge than White caregivers. *T*-tests showed that there were statistically significant differences between the racial groups on two of these items—caregiver's energy level and child's energy level (see Figure 3). Additionally, a significant difference (p = .012) between the racial groups was found on the question regarding caregiver's knowledge of child's medical needs after discharge; in particular, non-White caregivers reported more knowledge of their children's post-discharge medical needs than White caregivers (non-Whites, M = 9.68; Whites, M = 9.21).

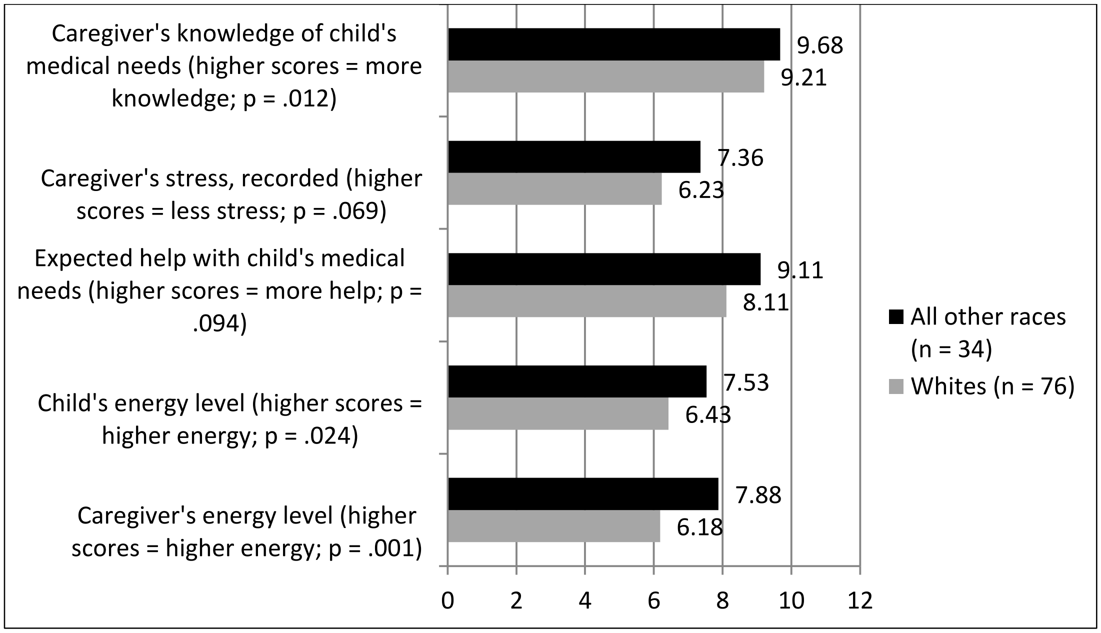

Figure 3. Readiness for Hospital Discharge Scale responses according to caregiver's race.

With regard to income, study participants with household incomes of $39,999 or less per year had mean scores at least 1 point higher than respondents in the higher (≥ $40,000) income category on two of the RHDS items. The lower-income group reported lower caregiver stress and higher child energy levels compared to the higher-income group. The difference in child energy level was statistically significant (*p* = .009), but the difference in caregiver's stress was not (*p* = .071; see Figure 4). Based on *t*-tests, the two income groups also had significant differences on two other RHDS items: caregiver energy level and ability to handle life demands at home. Caregivers in the lower-income group reported a higher energy level at the time of discharge compared to those in the higher-income group (lower income, *M* = 7.10; higher income, *M* = 6.11; *p* = .034). Lower-income caregivers also indicated a greater ability to handle the demands of life at home than higher-income caregivers (lower income, *M* = 9.55; higher income, *M* = 9.13; *p* = .014).

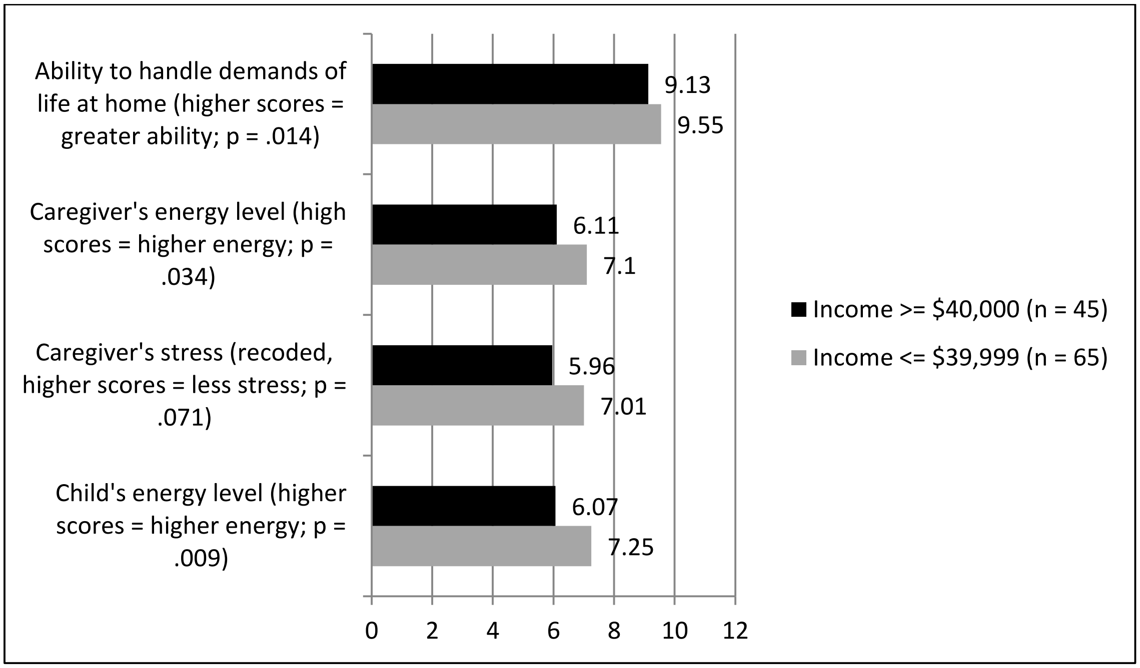

Figure 4. Readiness for Hospital Discharge Scale responses based on household income.

Aim 2 Results

The second aim was to investigate the relationship between caregiver health literacy and caregivers' post-discharge coping. The Pearson correlation between the Self-Reported Health Literacy Measure and the Post-Discharge Coping Difficulty Scale (PDCDS) scores was -.124 (*p* = .137). Higher scores on the Self-Reported Health Literacy Measure indicate lower health literacy, while higher PDCDS scores signify greater difficulty experienced following hospital discharge. The negative correlation between caregiver health literacy and post-discharge coping difficulty means that as health literacy scores increased (i.e., as health literacy decreased), post-discharge coping decreased (i.e., less difficulty experienced after hospital discharge).

To explore this relationship in the presence of other possible predictors, a linear regression was performed. The relationships between post-discharge coping and each of the following eight predictors were tested: caregiver health literacy, readiness for hospital discharge (measured by the RHDS), income ($\leq$\$39,999/$\geq$\$40,000), race (White/All other races), child's age, number of adults living in the home, number of children in the household, and prior hospitalizations for the same diagnosis (yes/no). Health literacy was not a significant predictor of post-discharge coping difficulty ($p = .391$), nor was readiness for hospital discharge ($p = .051$). Of the other covariates, race was a significant predictor of post-discharge coping difficulty ($p = .005$). The entire model was statistically significant ($R^2 = .313$, $p = .001$).

All of the continuous variables in the regression, including the PDCDS scores, were skewed. Normalizing transformations were applied to all of the continuous variables, and the regression was repeated using the transformed variables. This model was also significant ($R^2 = .390$, $p < .001$). Health literacy again had a very small, nonsignificant effect on post-discharge coping difficulty ($p =.355$). Among the covariates, race ($p = .001$), readiness for hospital discharge ($p = .029$), and child's age ($p = .009$) were statistically significant (see Table 4).

Table 4

Multiple Regression Results of Normalized PDCDS Score

Variable	Estimate	*SE*	*p*
Caregiver health literacy (normalized)	-.101	.109	.355
RHDS score (normalized)	.273	.122	.029*
Child's age (normalized)	-.122	.045	.009*
No. adults in household (normalized)	-.030	.099	.760
No. children in household (normalized)	.075	.077	.329
Annual household income (dichotomous)	-.022	.037	.554
Caregiver race (dichotomous)	-.139	.040	.001*
Prior hospitalization for same diagnosis (dichotomous)	-.021	.049	.676

Note. PDCDS = Post-Discharge Coping Difficulty Scale; RHDS = Readiness for Hospital Discharge Scale.
*Significance at .05 level.

As with Aim 1, the effects of health literacy and three significant variables—race, readiness for hospital discharge, and child's age—on individual items in the PDCDS were explored. Higher scores on the questions that make up the PDCDS signify greater coping difficulty for the caregiver and/or other family members. The dichotomized health literacy variable previously described was used for this analysis. Persons in the adequate health literacy group had mean scores of at least 1 point higher (on a 0–10 scale) than those with low health literacy on three of the 11 scored items in the PDCDS. These differences were not statistically significant (see Figure 5).

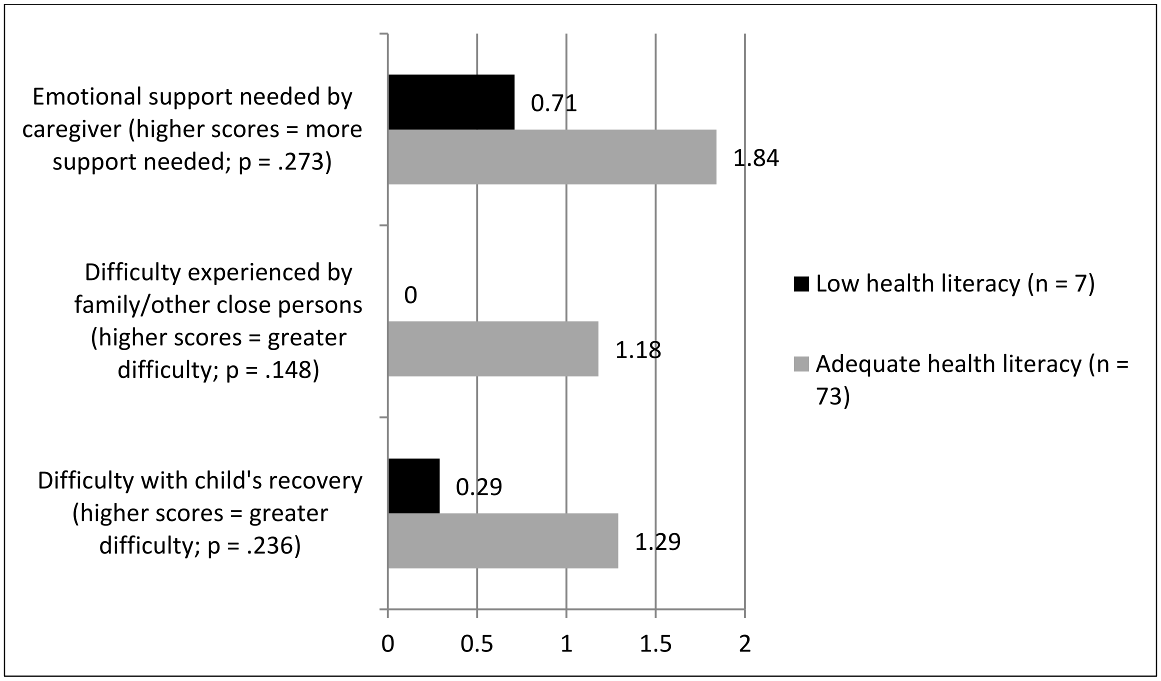

Figure 5. Post-Discharge Coping Difficulty Scale responses based on caregiver health literacy.

In terms of race, mean scores on all 11 items of the PDCDS were higher for White caregivers than for non-White caregivers. The means were at least 1 point higher (representing statistically significant differences between the racial groups) on four items: emotional support needed by the caregiver, difficulty experienced by family members/other close persons, difficulty with child's recovery, and life stress since discharge (see Figure 6). There was also a statistically significant difference between the groups on two additional PDCDS items: difficulty caring for the child after discharge ($p = .018$) and caregiver confidence in caring for the child's needs at home ($p = .038$). Minority caregivers reported less difficulty caring for their children post-discharge than White caregivers reported ($M = 0.07$ vs. $M = 0.53$, respectively). Caregivers of diverse racial backgrounds also stated that they were more confident in their ability to care for their child's needs ($M = 0.148$) compared to White caregivers ($M = 0.698$); lower scores on this item represent greater confidence as this question was recoded to align with the overall scoring of the instrument.

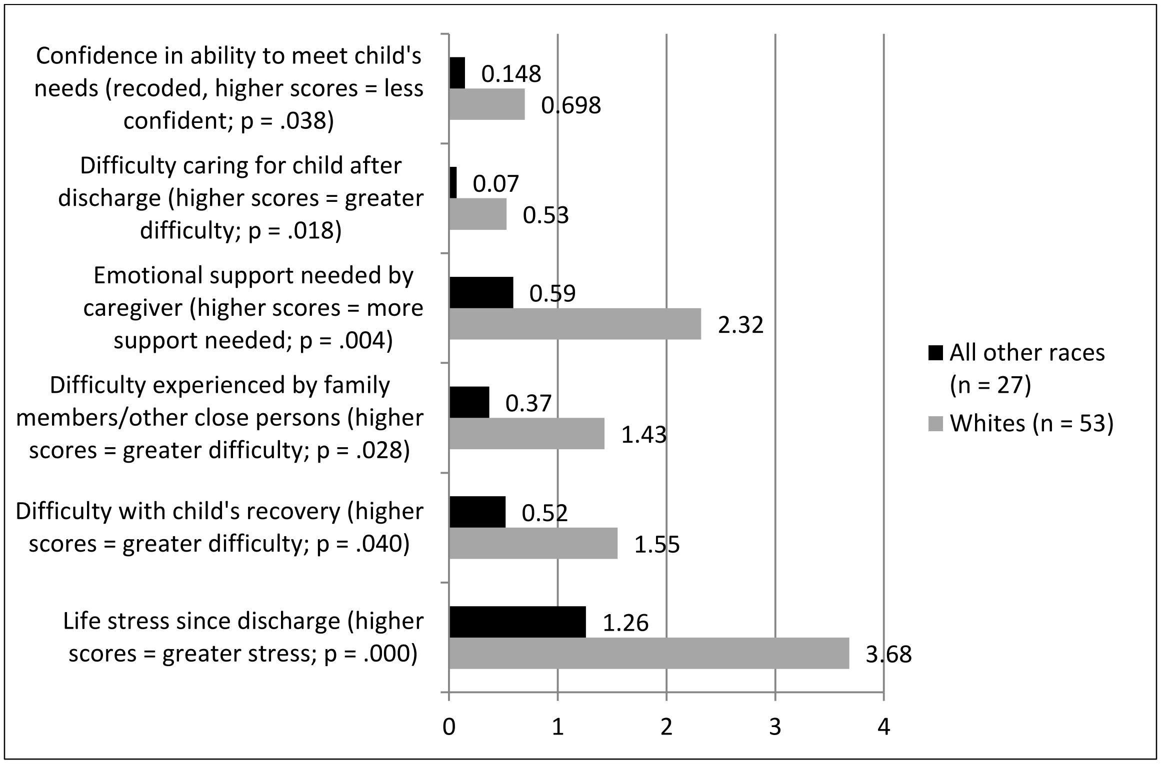

Figure 6. Post-Discharge Coping Difficulty Scale responses based on caregiver’s race.

To further explore the relationship between readiness for hospital discharge and post-discharge coping difficulty, a dichotomized version of the Readiness for Hospital Discharge Scale (RHDS) variable was created. Existing research conducted by the developer of the RHDS and PDCDS instruments indicates that the RHDS variable has been dichotomized in the past with a cut-off score of 7 (Bobay, Jerofke, Weiss, & Yakusheva, 2010). RHDS scores of less than 7 indicate low readiness for discharge, while scores in the 7 range suggest some deficiencies and scores of 8 or higher imply readiness for discharge (M. Weiss, personal communication, July 28, 2015). These values reflect a total item mean rather than a total scale score for the RHDS. This dichotomization and the resulting total item mean are one way the instrument developer has reported readiness for discharge in the literature (Weiss et al., 2008). Because total *item* means are presented on a 0–10 scale, results are easier to interpret than total *scale* scores, which range 0–290.

In this study, it was not possible to use a cut-point of 7 to create the dichotomous RHDS variable in the manner describe above; doing so would have resulted in only 2 persons in the “not ready for discharge” (< 7 total item mean) group. Instead, 7.5 was used as the cut-point for dichotomization—only slightly different than the division suggested by Weiss. When the RHDS variable was dichotomized using 7.5 as the cut-point, 7 caregivers fell in the not-ready-for-discharge group and 73 in the ready-for-discharge group. The not-ready caregivers had higher mean scores on eight of the 11 PDCDS items than those in the ready group. There was a more-than-1-point difference between these two groups’ means for two questions: the question of emotional support needed by the caregiver after discharge and the question of difficulty experienced during the child’s recovery. Both of these differences were statistically significant (see Figure 7). There was also a statistically significant difference between the two groups on the PDCDS item regarding caregiver ability to care for the child’s medical needs (p = .005). Caregivers who perceived themselves as ready for discharge felt better able to care for their child’s medical needs at home (M = 0.014) compared to caregivers who did not feel ready for discharge (M =0.286); lower scores on this item indicate a greater ability to care for the child’s needs, as this item was recoded to fit with the overall scoring of the instrument.

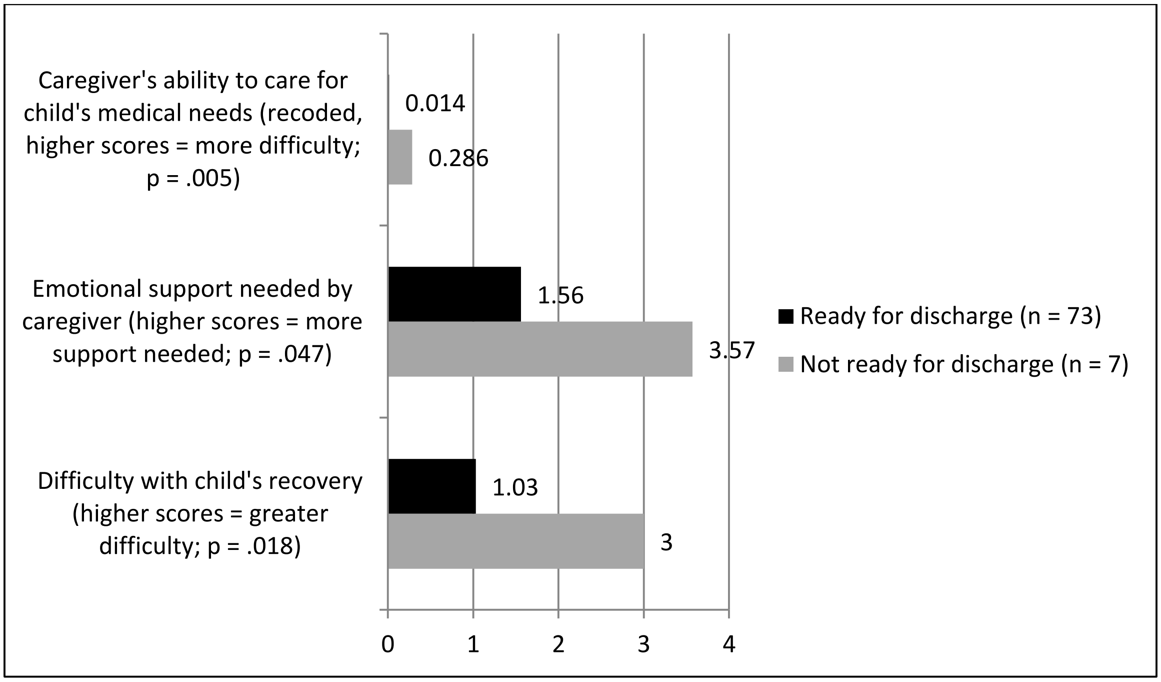

Figure 7. Post-Discharge Coping Difficulty Scale responses based on caregiver's readiness for discharge.

For this analysis, a dichotomized variable for the child's age was created, based on whether the child was of school age or not. Among the children in the sample, 61 were younger than 6 years old, and 19 were 6 years old or older. On all 11 items on the PDCDS, caregivers of children in the younger (< 6 years old) group had higher mean scores than those of the older (≥ 6 years old) children, and the means were more than 1 point higher on two items. Caregivers of younger children required more emotional support and experienced greater difficulty with their child's recovery than did caregivers whose hospitalized child was 6 years old or older. The differences between the two groups on these items were both statistically significant (see Figure 8). There was also a significant difference between the groups on the PDCDS item that relates to the amount of help with caring for the child at home (*p* = .010). Caregivers of younger children reported needing more help (*M* = 1.07) compared to caregivers of older children (*M* = 0.11), as higher scores indicate more help needed.

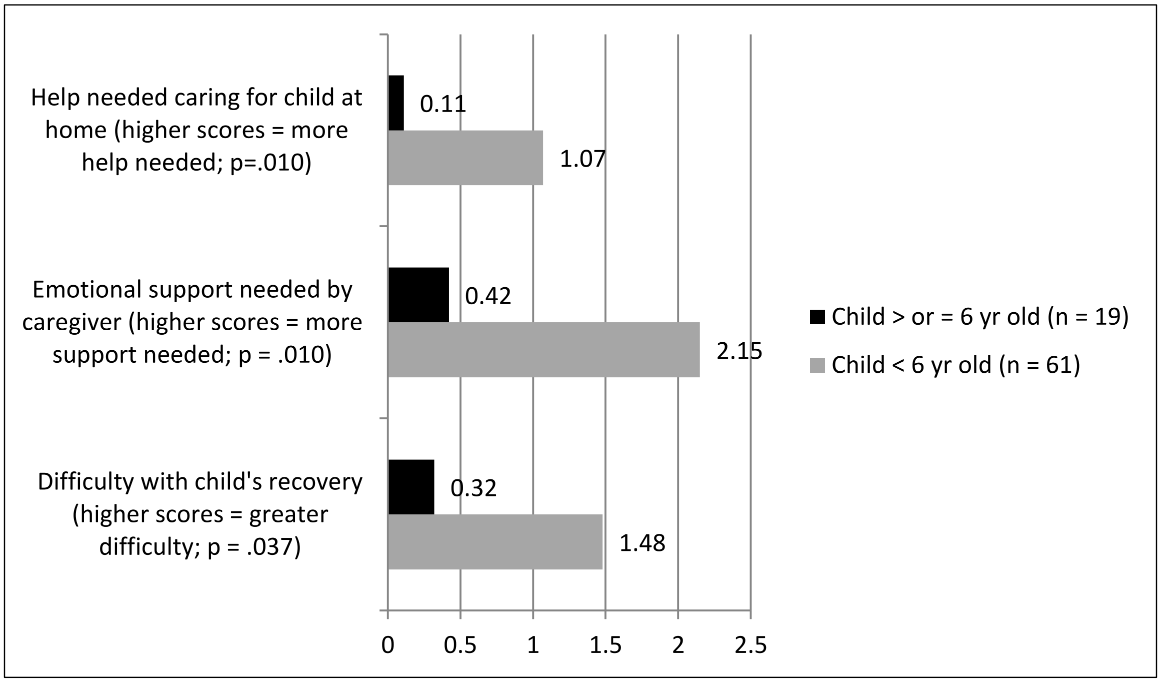

Figure 8. Post-Discharge Coping Difficulty Scale responses based on child's age.

Aim 3 Results

The third aim was to investigate the relationship between caregivers' health literacy and their utilization of health services for their child after the child's hospital discharge. Utilization of health services was measured with the Post-Discharge Utilization of Healthcare Resources instrument, which is normally used in conjunction with the Post-Discharge Coping Difficulty Scale (PDCDS). A logistic regression was performed to assess the impact of various factors on the likelihood that participants needed to call family or friends for advice or support after their child was discharged from the hospital. The model contained four independent variables: caregiver's health literacy, caregiver's age, child's age, and caregiver's race (White/All other races).

The full model containing all predictors was statistically significant ($\chi^2 = 18.389$, *df* = 4, *p* = .001), indicating that the model distinguishes, better than the null model of just a constant, between participants who reported needing to call family or friends for advice or support and those who did not need to call. The Cox and Snell R-squared and the Nagelkerke R-squared values were 19.3% and 26.1%, respectively, for the full model, and the full model correctly classified 68.6% of cases. In this analysis, health literacy did not prove to be a significant predictor in determining who would need to contact family or friends after hospital discharge (*p* = .652).

Table 5

Predictors of Calls to Family/Friends Post-Discharge Using Logistic Regression

Criteria/predictor variable	*B*	*SE*	*Wald*	*df*	*p*	*Exp(B)*
Caregiver's health literacy	-.058	.129	.203	1	.652	.944
Caregiver's age	-.041	.039	1.102	1	.294	.960
Child's age	-.203	.097	4.341	1	.037*	.817
Caregiver's race (dichotomous)	-.886	.574	2.382	1	.123	.412

**Note*. Significance at .05 level.

As shown in Table 5, the child's age was the only independent variable that made a unique statistically significant contribution to the model (*p* = .037). The odds ratio of 0.817 for the child's age was less than 1, indicating that for every additional year of the child's age, the odds that a participant would contact family or friends for advice or support were reduced by approximately 20%, when controlling for other factors in the model.

In the above-described analysis, sufficient numbers of persons were in the user and nonuser groups (i.e., those who used family or friend support by calling on them after discharge and those who did not use such support) to perform logistic regression. However, this was not the case for the other utilization variables. For the remaining analyses, exact chi-square tests were performed on caregivers' utilization (yes/no) of each type of health service (call or visit to a regular doctor's office, calls to the hospital, use of urgent care/emergency room services, and hospital readmission) and health literacy (adequate/low). Only those who participated in the follow-up phone call—86 of the 123 study participants (69.9%)—were included in these analyses, because the information about use of health services after discharge was collected during that portion of the study.

Upon performing an exact chi-square test, the relationship between a caregiver's health literacy and calling or visiting the doctor following their child's hospitalization was found to be statistically significant ($\chi^2 = 10.331$, $df = 1$, $p = .015$). This result implies that caregivers' health literacy affects the likelihood that they will seek the recommended hospital follow-up with the child's doctor, either in person or by phone, after hospital discharge. Of the caregivers with adequate health literacy, 93.8% ($n = 75$) indicated they had called or visited their child's doctor since leaving the hospital, whereas only 57.1% ($n = 4$) of those with low health literacy had made such a call or visit (see Table 6).

Table 6

Relationship of Caregiver Health Literacy and Doctor Calls/Visits, Using χ^2

Called/visited child's doctor post-discharge	Health literacy group	
	Adequate (*n* = 80)	Low (*n* = 7)
Yes	75 (93.8%)	4 (57.1%)
No	5 (6.3%)	3 (42.9%)

An exact chi-square analysis on caregiver health literacy vis-à-vis making calls to the hospital about a medical problem after discharge showed a relationship that was not statistically significant (χ^2 = .275, *df* = 1, *p* = 1.000). Of the 86 persons responding to this question, only 3 reported calling the hospital after taking their child home, all of whom were in the adequate health literacy group (see Table 7).

Table 7

Relationship of Caregiver Health Literacy and Hospital Calls Post-Discharge, Using χ^2

Called hospital after discharge	Health literacy group	
	Adequate (*n* = 79)	Low (*n* = 7)
Yes	3 (3.8%)	0
No	76 (96.2%)	7 (100%)

Exact chi-square analysis also showed that there was not a statistically significant relationship between caregiver health literacy and caregivers' seeking care for their child in an urgent care center or hospital emergency room after discharge (χ^2 = .119, *df* = 1, *p* = 1.000). Nine caregivers reported taking their child to an urgent care center or hospital emergency room post-discharge; 8 of these 9 caregivers were in the adequate health literacy group, and 1 was in the low health literacy group (see Table 8).

Table 8

Relationship of Caregiver Health Literacy and Utilization of Urgent Care/ER Services, Using χ^2

Used urgent care/ER after discharge	Health literacy group	
	Adequate (*n* = 79)	Low (*n* = 7)
Yes	8 (10.1%)	1 (14.3%)
No	71 (89.9%)	6 (85.7%)

Finally, an exact chi-square test determined that the relationship between the variables of caregiver health literacy and readmission of the child after hospital discharge was not statistically significant (χ^2 = .470, *df* = 1, *p* = 1.000). This result suggests no relationship between caregiver health literacy and a child's readmission to the hospital. In this study, 5 out of 86 caregivers reported their child had been readmitted to the hospital after the first discharge. The caregiver of each child who was readmitted was in the adequate health literacy group (see Table 9).

Table 9

Relationship of Caregiver Health Literacy and Child's Hospital Readmission, Using χ^2

Readmission to hospital after discharge	Health literacy group	
	Adequate (*n* = 79)	Low (*n* = 7)
Yes	5 (6.3%)	0
No	74 (93.7%)	7 (100%)

CHAPTER V: DISCUSSION

Sample Characteristics Based on Caregiver Health Literacy

Caregiver health literacy was the emphasis of this research. In addition to reporting basic demographic information about the participants, the study examined the sample in terms of caregivers' health literacy levels. There was a statistically significant difference in the mean age of caregivers in the adequate health literacy group and those in the low health literacy group. The adequate health literacy group had a lower mean age of caregivers than that of the low health literacy group (31.04 years vs. 37.30 years). This was not surprising, as older age has been associated with low health literacy in the past. However, in this study, even though those with low health literacy were older, they were still relatively young (in their 30s). This comparatively low mean age for the low health literacy group is likely due to the fact that this was a study conducted on a pediatrics unit; parents of young or school-age children will tend to be younger themselves in comparison to the overall adult population.

Among study participants, a statistically significant difference in the child's age between caregivers in the adequate and low health literacy groups was also observed. The mean age of children of caregivers in the adequate health literacy group (M = 3.50 years) was less than the mean age of the children of caregivers in the low health literacy group (M = 7.24 years). This difference might be attributable to the variance in the size of the two groups and/or the young age of the children represented by caregivers in the study. In particular, there were 113 caregivers in the adequate health literacy group but only 10 caregivers in the low health literacy group. The overall mean age of the children (from either group) was 3.81 years, indicating that a majority of the children of the caregivers in the study were younger pediatric patients.

Besides the ages of the caregiver and child, caregiver education level was a third variable displaying a significant difference between the adequate health literacy and low health literacy groups. Caregivers in the adequate health literacy group had attained higher levels of formal education compared to caregivers in the low health literacy group. None of the caregivers in the low health literacy group had graduated from college, whereas caregivers in the adequate health literacy group had education levels ranging from less than high school to doctoral degrees. Although the number of caregivers in the low health literacy group was small (*n* = 10), this finding aligns with existing knowledge that those with less education are at risk for low health literacy.

Caregiver Health Literacy and Readiness for Hospital Discharge

One of the primary aims of this research was to investigate the relationship between caregiver health literacy and readiness for hospital discharge. Prior to this study, no research was known to have explored the connection between these factors. Predictors selected for inclusion in this analysis were chosen based on previous research involving discharge readiness. Findings from studies conducted by the developer of two of the main instruments used in this study, the Readiness for Hospital Discharge Scale (RHDS) and the Post-Discharge Coping Difficulty Scale (PDCDS), suggested there are other, yet to be identified considerations that should be made when evaluating discharge readiness (Weiss et al., 2008).

Many children are prescribed medications to take at home after being discharged from a hospitalization, making it essential for nurses to ensure parental understanding of the medication regimen prior to discharge. Although existing research indicates a connection between low health literacy and parental medication errors, health literacy was not a significant predictor of readiness for discharge in this study. One explanation for why health literacy did not end up being related to readiness for hospital discharge is because readiness for discharge (as determined by the RHDS) encompasses much more than the caregivers' ability to administer medications (e.g., knowledge of the child's growth and development needs, awareness of problems to watch for in the child after going home, and understanding of the child's follow-up treatment plan after discharge).

Even though the correlation between health literacy and readiness for discharge was not statistically significant, the negative correlation indicates that the relationship between these concepts is in the direction hypothesized by the researcher, as health literacy decreased, so did readiness for discharge. This relationship was further explored by examining participants' responses to items on the RHDS according to their health literacy levels (adequate vs. low). Caregivers in the adequate health literacy group reported a lower stress level at the time of hospital discharge (on average) compared to those in the low health literacy group; however, this difference was not statistically significant. One interpretation of this finding may be that caregivers with adequate health literacy felt comfortable with the teaching and discharge instructions delivered in the hospital, and with the subsequent care that they would need to provide. An alternative explanation might be that caregivers in the adequate health literacy group had good social support systems, resulting in lower stress about caring for their child after hospitalization. Caregivers in the low health literacy group, meanwhile, reported a greater mean strength level than those with adequate health literacy. This finding also was not statistically significant. Having a child in the hospital is known to be difficult for caregivers, as they often must balance the needs of the hospitalized child with other life demands, including the needs of other children and/or family members. Caregivers with low health literacy may have had support persons able to take on some of their other "outside-the-hospital" responsibilities, thereby freeing them to focus on the hospitalized child and the care he or she would need after returning home. While the RHDS contains items that gauge the amount of help caregivers expect to have at home, this study did not specifically assess participants' support systems. Thus, it is impossible to ascertain if the differences in caregivers' stress and strength between the two health literacy groups can be explained by the amount of help they had outside of the hospital.

Although the two between-group differences discussed above were not statistically significant, there was a significant difference between the two groups in terms of physical readiness for discharge. Caregivers in the adequate health literacy group reported being more physically ready to go home than caregivers in the low health literacy group. This finding may be explained by the fact that these caregivers felt prepared to care for their child at home because of the thoroughness of the instruction provided in the hospital and/or because of the level of support they anticipated after discharge.

Of the other variables included in the analysis, race and income were the only two that were statistically significant in predicting readiness for hospital discharge. Existing research has not shown a connection between race and/or income and discharge readiness. Race and income were dichotomized (Whites/All other races; ≤ $39,999/ ≥ $40,000), and differences between the groups on individual RHDS items were examined.

In regards to race, caregivers of diverse races (*n* = 34, 30.9%) reported a lower mean stress level at discharge compared to Whites (*n* = 76, 69.1%). Additionally, caregivers from various racial backgrounds indicated that they expected to receive more help with their child's medical needs after discharge than did White caregivers. Caregivers who anticipated more help upon returning home, understandably, may have been less stressed about leaving the hospital environment. These minority caregivers reported higher mean energy levels for themselves and for their children compared to White caregivers. Both of these between-group differences were statistically significant. Return of energy or increased activity level is often indicative of improvement in a child's health status. These caregivers noted higher energy levels in their children, an observation that may have provided reassurance of their children's readiness for discharge, which, in turn, might also reduce the caregivers' stress about assuming responsibility for follow-up medical care required at home. There was also a significant difference between the racial groups in terms of caregivers' knowledge of their child's medical needs after discharge. Caregivers from diverse racial backgrounds reported having more knowledge about their child's medical needs compared to White caregivers. This knowledge may have come from previous hospitalizations and/or experiences with the child's condition, and/or information learned during the most recent hospitalization.

Concerning the relationship between household income and readiness for hospital discharge, caregivers in the lower-income group ($\leq$ \$39,999) reported a lower mean stress level than those in the higher-income group ($\geq$ \$40,000). Although some may have difficulty understanding this finding, those in the lower-income group could have received governmental assistance (e.g., Medicaid) that enabled them to meet their children's health care needs despite limited financial resources. Having confidence in their ability to provide for their children possibly resulted in a lower level of stress with respect to discharge from the hospital. Another potential explanation is multiple generations residing in the same household—not uncommon among lower-income families. Not only would this situation result in shared living expenses, but it would also afford lower-income families greater support and help with household responsibilities, which in turn can result in lower caregiver stress. Additionally, caregivers in the lower-income group reported higher mean energy levels for themselves and their children when compared to the higher-income group. Caregivers in the lower-income group indicated a greater ability to handle the demands of life at home compared to caregivers in the higher-income group. These differences between caregiver groups also might be explained by the close relationships that are common among members of lower-income families, as previously discussed.

Caregiver Health Literacy and Post-Discharge Coping

The second aim of this study was to examine the relationship between caregiver health literacy and post-discharge coping. Data for this analysis were collected via a follow-up phone call, conducted approximately 3 weeks after the child was discharged from the hospital. Due to the longitudinal aspect of this portion of the study, not all participants were able to be reached for follow-up. Because of the smaller number of participants in this phase of the study (*n* = 87, 70.7%), fewer predictors were allowable for the statistical analyses related to this research aim. Correlations between the variables were used to determine which predictors to include, and the variables with the highest correlations were retained in the analyses.

There was a nonsignificant negative correlation between caregiver health literacy and post-discharge coping difficulty: as health literacy decreased, post-discharge coping difficulty also decreased. In other words, caregivers with low health literacy had less difficulty coping post-discharge than did caregivers with adequate health literacy. This finding is not intuitive and, indeed, is the opposite of what one might expect.

Although caregivers' health literacy was hypothesized to affect their coping and ability to care for their child after discharge, in this study, health literacy did not prove significantly related to caregivers' coping after the child's hospitalization. Existing research has shown that caregivers do not always understand the discharge instructions given prior to leaving the hospital (Chappuy et al., 2012; Zavala & Shaffer, 2011). This information provided the rationale for exploring the relationship between caregiver health literacy and post-discharge coping as one aspect of this research. The absence of a significant relationship between these concepts in this study may be attributed to staff (including nurse) efforts in the study site's pediatrics unit to prepare caregivers to take care of their child at home. The lack of a significant relationship may also be due to the number of participants able to be contacted for the follow-up phone call (87 out of the total sample of 123). This research was conducted as a naturalistic longitudinal study, and no data were collected regarding the nurses' typical efforts to prepare patients and families for discharge.

Despite the fact that health literacy was not significant in predicting post-discharge coping in this study, additional evaluation was performed to consider caregivers' responses to individual questions on the Post-Discharge Coping Difficulty Scale (PDCDS) based on their health literacy level (low vs. adequate). Caregivers with adequate health literacy reported greater difficulty with the child's recovery than did caregivers with low health literacy. Additionally, caregivers in the adequate health literacy group indicated that their family members and other close persons also experienced greater difficulty following the child's discharge than did those in the low health literacy group. These findings were somewhat surprising. One would expect caregivers who are more readily able to understand, use, and therefore follow health-related information provided in the hospital pre-discharge might experience less difficulty caring for the child at home, not more difficulty. These results lend support to another difference noted between the two health literacy groups: caregivers in the adequate health literacy group needed more emotional support after discharge compared to caregivers in the low health literacy group. Thus, caregivers who have difficulty caring for their child might require greater emotional support than caregivers who report less trouble post-hospitalization.

Of the other variables included in these analyses, three reached statistical significance. Caregiver race was a significant predictor of post-discharge coping difficulty. Readiness for hospital discharge became significant in analyses that were conducted using the transformed variables as discussed in Chapter IV. The age of the child who had been hospitalized was also statistically significant in predicting post-discharge coping difficulty when the transformed variables were used. Differences between the groups on individual PDCDS items were examined using the following dichotomized forms of these variables: caregiver race (Whites/All other races), readiness for hospital discharge (ready/not ready), child's age (< 6 years old/≥ 6 years old).

Regarding race, White and minority caregivers showed noticeable differences on 6 of the 11 scored questions on the PDCDS. White caregivers reported greater difficulty with the child's recovery and more difficulty caring for their child after discharge than did caregivers of other races. Whites also indicated that their family members and other close persons experienced more difficulty after the child came home from the hospital than did caregivers of other races. White caregivers reported experiencing a higher level of life stress following hospital discharge than minority caregivers. The above findings correspond with one another and lend support to two additional differences noted between the two groups: White caregivers admitted to both needing more emotional support after bringing their child home from the hospital and having less confidence in their ability to meet their child's needs compared to minority caregivers. To date, no known studies have specifically looked at the relationship between race and post-discharge coping; existing research indicates that persons of lower socioeconomic status and those who experience greater life stress have more difficulty with the post-hospital transition (Kangovi et al., 2014).

Readiness for hospital discharge was the focus of this study's first aim and was determined using the RHDS. Based on the analyses conducted, discharge readiness levels may be able to predict caregivers' difficulties after leaving the hospital. Caregivers who were not ready for discharge had higher mean scores on 8 of the 11 PDCDS items, where higher scores indicate greater coping difficulty. Caregivers in this "not-ready" group reported needing more emotional support after discharge than did caregivers who perceived themselves as ready for discharge. Additionally, those in the not-ready group relayed greater difficulty with the child's recovery and more difficulty meeting their child's medical needs than caregivers in the "ready" (for discharge) group. These findings were consistent with each another, as having more trouble post-hospitalization could certainly explain caregivers' need for extra emotional support. Furthermore, caregivers who did not feel prepared to assume care for their child outside the hospital environment were likely to experience greater difficulties post-discharge.

Regarding age of the child, three questions on the PDCDS showed noticeable differences in answers between caregivers of younger children and caregivers whose children were school-age or older. Caregivers of children under 6 years old reported more difficulty with their child's recovery than caregivers of older children did ($\geq$ 6 years). Also, caregivers of younger children indicated a greater need for help caring for their child and a greater need for emotional support for themselves. These findings are reasonable when considered in the context of developmental theory, specifically Erikson's theory of psychosocial development. The five stages and corresponding age ranges that comprise this theory were used to guide the creation of the dichotomized child's age variable (< 6 years/$\geq$ 6 years) for part of this study. The first stage of Erikson's theory, Trust versus mistrust, begins at birth and lasts through the first year of life. In this stage, caregivers' ability to consistently and adequately meet a child's needs leads to the development of trust and lays the foundation for future personality and psychosocial development. Younger children, especially newborns and infants, are dependent on their caregivers for all their basic needs, and they tend to require more physical care and attention than older children. Even as children grow and transition into the two subsequent stages of Erikson's theory, Autonomy versus shame and doubt (ages 1–3 years) and Initiative versus guilt (ages 3–6 years), they require a great deal of attention and help from their caregivers, which supports the study findings relative to caregivers of younger children discussed above (Franklin & Prows, 2013).

Caregiver Health Literacy and Post-Discharge Utilization of Healthcare Resources

A third aim of this research was to determine if caregivers' health literacy levels could be used to predict their utilization of various health-related resources and services after discharge. As for the second aim, data connected to this third aim were also collected during the follow-up phone call. Because not all caregivers were able to be contacted by phone, statistical analyses were adjusted to account for the number of persons who participated in the post-hospital portion of the study.

Statistical procedures were performed to determine if selected variables could predict the caregivers who would need to call family or friends for advice or support after their child was discharged from the hospital. Health literacy, as the overall focus of this study, was included in this analysis. The relationships between using this type of support and three other variables—caregiver's age, caregiver's race, and child's age—were investigated as well. Each of these variables was selected because of being significantly correlated with the PDCDS item about calling family or friends for support or advice after discharge. Caregiver health literacy was not found to be a significant predictor of this type of support. Of the variables included in this analysis, child's age was the only one that was statistically significant. Caregivers of younger children were more likely to contact family members or friends, and the likelihood of needing advice or support from others decreased as the child's age increased. Shorter postpartum hospital stays have resulted in less time for nurses to teach caregivers, especially first-time parents, how to care for their newborn after hospital discharge (Wheeler, 2013). More significant physical and developmental changes occur in a person’s infancy than at any other time in his or her life span. Even beyond the newborn period, caregivers of younger children commonly have questions and need additional support as they care for their children. Nurses in various settings can answer caregivers’ questions as well as provide anticipatory guidance to help parents prepare for upcoming developmental needs of their child (Wilson, 2013). This situation, as a whole, helps explain why caregivers of younger children might have a greater need for advice or support after their child is discharged compared to caregivers of older children.

Data from the remaining PDCDS variables were analyzed using exact chi-square tests. Use and nonuse of each type of health service or resource was evaluated in light of caregivers’ health literacy (using the dichotomized variable: adequate vs. low). The relationship between caregiver health literacy and calling or visiting the child’s doctor after discharge was assessed. There was a statistically significant relationship between these variables. In general, all caregivers of children who are discharged from the hospital are instructed to follow up with their primary care physician or other health care professional after leaving the hospital. Among the caregivers in the adequate health literacy group, 93.8% *(n* = 75) sought the recommended follow-up for their child, whereas only 57.1% *(n* = 4) of caregivers in the low health literacy group contacted their child’s health care provider (see Table 6). These findings clearly show that caregivers with an adequate level of health literacy understand the importance of obtaining the recommended post-hospital care for their child. Although this finding is not surprising, it is necessary to acknowledge that the number of caregivers determined to have low health literacy was small (7); therefore, the results may be skewed.

Routinely, when children are discharged from the hospital unit where this study was conducted, caregivers are given the phone number for the pediatrics unit and told they can call if they have questions or problems after getting home. In this study, the relationship between caregiver health literacy and needing to call the hospital about a medical problem after discharge was not statistically significant. Of the 86 participants who responded to this question, only 3 caregivers, all of whom were in the adequate health literacy group, reported calling the hospital after discharge. Although one might predict that caregivers in the low health literacy group would be the ones to call the hospital about medical problems, such was not the case in this study.

Prior research has been done to identify factors associated with use of the hospital emergency room for routine health care. This study investigated the relationship between caregivers' health literacy and seeking care for their child in an urgent care center or hospital emergency room after discharge from the hospital. No statistical significance was found between these variables. Of the 86 caregivers who responded to this question, 9 (10.5%) reported taking their child to an urgent care facility or hospital emergency room since the first discharge. One might expect these caregivers to have been in the low health literacy group, by the reason that those with less health literacy may have more difficulty determining the appropriate level of care needed (i.e., primary care office vs. urgent or emergency care services). Instead, 8 of these 9 caregivers who took their child to one of these higher-level-care facilities were in the adequate health literacy group. One possible explanation for this finding may be that caregivers who have adequate health literacy tend to be more diligent, perhaps overly so, and might be more apt to overreact when considering healthcare options for their child.

Because of the high costs associated with inpatient care, hospital readmission rates are monitored by health care systems, and actions are taken to reduce the incidence of readmission. Hospitalization is a particularly stressful experience for a child, providing additional motivation to minimize the likelihood of readmission. To prevent re-hospitalization, caregivers must be able to provide the necessary medications and treatments prescribed at the time of discharge. Thus, one might expect caregivers with limited health literacy to struggle with meeting their child's medical needs at home. In this study, 5 out of 86 caregivers reported that their child had been readmitted to the hospital. All of the caregivers whose children were readmitted were in the adequate health literacy group. This result conflicts with the notion that readmission can be attributed, at least in part, to low health literacy among caregivers. Collection of specific information related to the children who were readmitted, the exact care they received after their initial discharge, and the circumstances surrounding their readmissions was beyond the scope of this study.

Study Findings and Meleis' Transitions Theory

Meleis' transitions theory was the theoretical framework selected to guide this research. Four types of transitions comprise this theory, including health/illness transitions, which a hospital discharge can be considered. In developing this study, the health literacy of caregivers was envisioned to be a transition condition; specifically, caregiver health literacy was seen as an aspect of preparation and knowledge listed among the factors that can facilitate or inhibit the transition process. Though caregiver health literacy was not found to be predictive of readiness for hospital discharge in this study, the negative correlation found between these variables suggests findings may be different if the study is repeated with another sample. Additionally, in this longitudinal study, not all caregivers could be reached for follow-up data collection, and this missing data may have affected study results.

Significance to Nursing

Based on a review of the literature and an examination of the existing studies on readiness for hospital discharge, it was projected at the outset of this study that caregiver health literacy would prove to be an important factor in determining readiness for hospital discharge and in post-discharge outcomes. Because nurses spend the greatest amount of time with patients and their families, they are largely responsible for preparing caregivers to take care of their children once they leave the hospital. In this study, caregiver health literacy was not significantly related to readiness for hospital discharge, post-discharge coping, or whether caregivers would need to call family or friends for advice or support after discharge. This is the first nursing study to examine the relationship of caregiver health literacy and readiness for discharge, and adds to what is known about each of these areas (health literacy and readiness for hospital discharge).

Because of the naturalistic design and specific aims of this study, detailed data on use of the teach-back process were not collected. The teach-back method has been shown to be an effective approach to ascertain caregivers’ understanding of information prior to discharge (Kornburger et al., 2013). Hospitals’ growing focus on better preparing patients and their caregivers for hospital discharge, coupled with findings from this research, serve as a foundation for continued work in the areas of health literacy and hospital discharge readiness.

Limitations of This Study

Several limitations of this research have been identified that likely affected the recruitment of study participants as well as the quantity and quality of data collected. The mean length of stay for the patients represented by the caregivers in this study was 1.77 days; some patients were even discharged the same day of admission to the hospital. Despite frequent visits to the hospital to recruit individuals for this study, short hospital stays made it impossible to approach some caregivers about participating in this study.

In addition to the above recruitment matters, some data collection issues may be perceived as limitations to this study. After caregivers agreed to participate in the study and signed the consent form, initial data collection took place in the hospital, with data ultimately collected on 123 participants. The second phase of the study required completion of a follow-up phone call after hospital discharge. Of the 123 caregivers who enrolled in the study, 87 (70.7%) were able to be reached for follow-up. In longitudinal research, some attrition is to be expected, but it is still important to acknowledge that losing some participants to follow-up may affect study findings.

The Post-Discharge Coping Difficulty Scale (PDCDS) used in the follow-up portion of the study was designed to be completed 3 weeks (21 days) after hospital discharge. The mean length of time between discharge and completion of the follow-up phone call was 39.8 days, or 5.7 weeks (range: 20–78 days, or 2.9–11.1 weeks). The variation in this interval between data collection time points may have affected the quality of the information gathered, particularly during the follow-up phone call. As time passed, caregivers may have had difficulty recalling specific details about their transition from the hospital back home and about their post-discharge coping.

The three instruments used in this study—the PDCDS, the Readiness for Hospital Discharge Scale (RHDS), and the Self-Reported Health Literacy Measure—are all based on self-report. Caregivers answered questions for themselves and for their children as they completed each tool. Data collection by self-report may have influenced the study findings as well. Research from the past 20 years (and possibly longer) has shown a stigma associated with low health literacy (Mackert et al., 2014; Parikh et al., 1996). As a result, caregivers may not have been completely forthcoming on the study instruments about their difficulties with reading, understanding, and/or utilizing health information. Further research is needed to better understand the shame associated with limited health literacy and to discern steps that can be taken to reduce health disparities in this population.

Recommendations for Future Research

Although caregiver health literacy was not significantly related to readiness for hospital discharge, caregivers' post-discharge coping, or utilization of health services after hospital discharge, this study is, nonetheless, a contribution to the research in each of these areas. Few studies have specifically addressed readiness for hospital discharge, and even fewer have done so in the pediatric realm. Even though health literacy itself was not predictive in this study, future research should be conducted to see if there are identifying characteristics of caregivers who report not being ready for discharge and who have difficulty coping after a child's hospitalization. Recognizing such traits, if any exist, would guide the development of nursing interventions aimed at improving caregivers' readiness for discharge.

Findings in this study likely were influenced by the fact that recruitment was conducted at a single, small pediatric unit where a minimally-diverse sample was obtained. This study should be repeated on a larger pediatric unit and/or at multiple pediatric centers simultaneously. Doing so would increase the likelihood that a more diverse sample would be recruited.

Future research could examine how well nurses prepare patients and families for discharge from the hospital. The developer of the RHDS and PDCDS tools used in this study has created another instrument, the Quality of Discharge Teaching Scale, that facilitates collection of data regarding patients' perceptions of the discharge teaching provided by the nursing staff. Additionally, repeating this research using instruments that are not all self-report measures could prove interesting. While no other validated instruments have been identified that assess either readiness for discharge or post-discharge coping, other health literacy instruments are available that could be utilized. The Self-Reported Health Literacy Measure was selected for use in this study to minimize participant burden, particularly in light of the number of items that make up the other study instruments (12 on the Demographic Information Form and 32 on the RHDS). Repeating this study using a different health literacy measure would be worthwhile, to see if the findings from this research are replicated.

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Appendix A

Demographic Information Form

Study ID# _____________ Project Title: Relationship of Caregiver Health Literacy to Readiness for Discharge Following a Child's Hospitalization

Demographic Information Form

Parent/Legal Guardian's Age: __________

Parent/Legal Guardian's Gender:

☐ Male ☐ Female

Parent/Legal Guardian's Race:

- ☐ Black or African American alone
- ☐ American Indian and Alaska Native alone
- ☐ Asian alone
- ☐ Native Hawaiian and Other Pacific Islander alone
- ☐ Two or More Races
- ☐ Hispanic or Latino
- ☐ White alone, not Hispanic or Latino

Parent/Legal Guardian's Marital Status:

- ☐ Married
- ☐ Divorced
- ☐ Never Married
- ☐ Widowed
- ☐ Separated

Parent/Legal Guardian's Highest Education Level Completed:

- ☐ Elementary School (Grades 1-8)
- ☐ Some High School (Grades 9-12)
- ☐ High School Graduate (or GED)
- ☐ Some College (Years 1-4)
- ☐ Associate's Degree
- ☐ Bachelor's Degree
- ☐ Master's Degree
- ☐ Professional School Degree
- ☐ Doctorate Degree

Number of Adults and Children Living in the Home:

Number of Adults (including yourself): __________

Number of Children: __________

Total Household Income per Year:

☐ Less than $20,000 ☐ $20,000 - $39,999 ☐ $40,000 - $59,999 ☐ $60,000 or more

Child's Age: __________

What is your relationship to the child?

☐ Mother ☐ Father ☐ Grandparent ☐ Foster Parent

☐ Other, (please specify): ____

Why is your child in the hospital?

____

____

____

How many days has your child been in the hospital? __________

Has your child ever been in the hospital for the same reason in the past?

☐ Yes ☐ No

Where will your child receive health care after he/she leaves the hospital?

☐ Pediatrician's Office ☐ Family Doctor's Office ☐ Johnson Health Center

☐ Other, name: ____

Telephone number where you can be reached after leaving the hospital

Area Code/Number: (______) _______-____________

Please provide a second phone number where you can be reached after leaving the hospital.
This can be your number or a family member/friend's number.

Area Code/Number: (   )   -

Appendix B

Readiness for Hospital Discharge Scale—Parent Form

Contact: Marianne Weiss, DNSc, RN
Marquette University College of Nursing
marianne.weiss@marquette.edu
(414) 288-3855

Appendix C

Post-Discharge Coping Difficulty Scale and Utilization of Healthcare Resources

Contact: Marianne Weiss, DNSc, RN
Marquette University College of Nursing
marianne.weiss@marquette.edu
(414) 288-3855

Appendix D

Self-Reported Health Literacy Measure

Study ID #______________________ SELF-REPORTED HEALTH LITERACY

⇨ Please check your answer to each question below.

1. How confident are you filling out medical forms by yourself?

☐ Not at all
☐ A little
☐ Somewhat
☐ Quite a bit
☐ Extremely

2. How often do you have problems learning about your medical condition because of difficulty understanding written information?

☐ Always
☐ Often
☐ Sometimes
☐ Rarely
☐ Never

3. How often do you have someone (like a family member, friend, hospital or clinic worker, or caregiver) help you read hospital materials?

☐ Always
☐ Often
☐ Sometimes
☐ Rarely
☐ Never

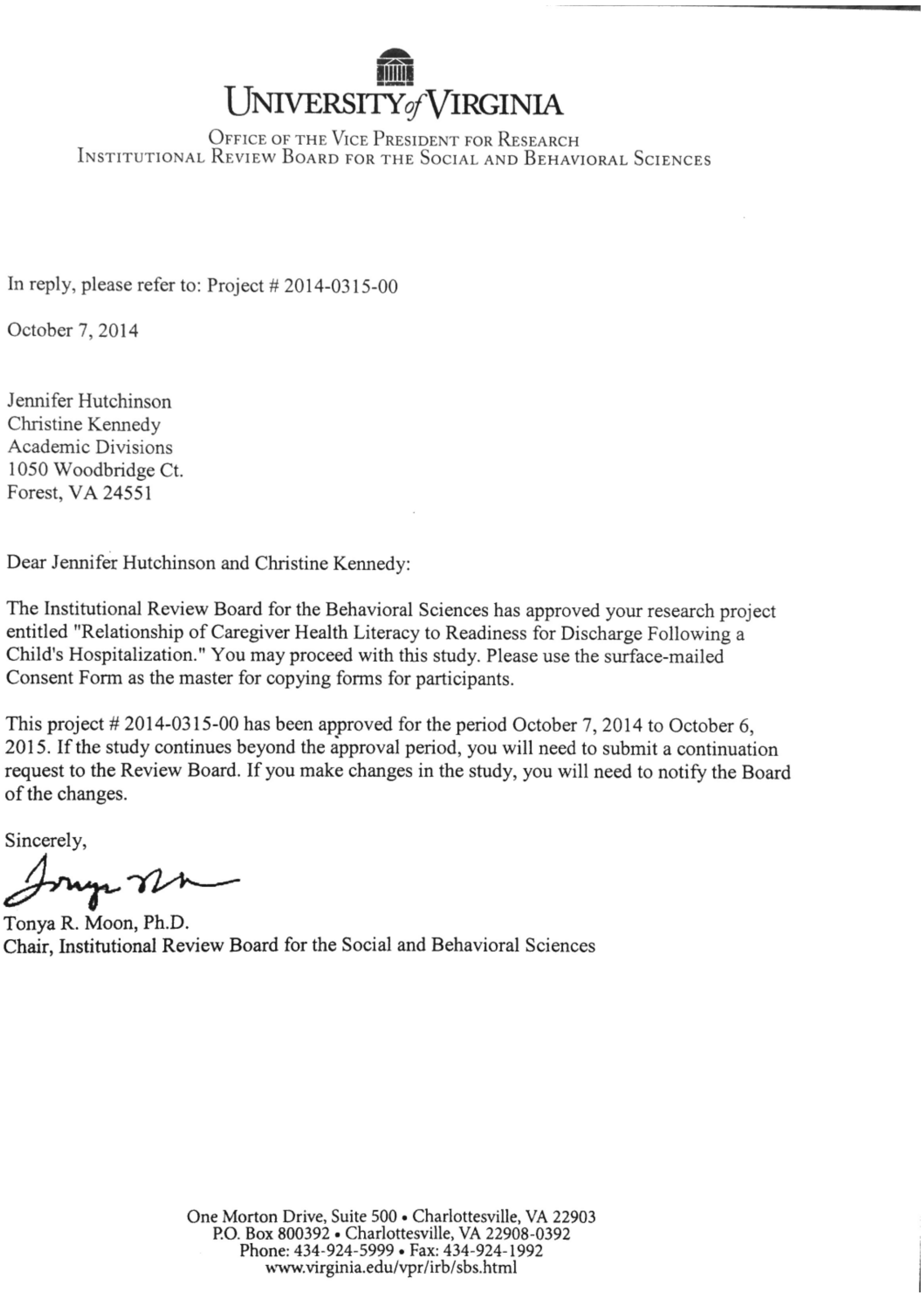
What is your relationship to the child?

☐ Mother ☐ Father ☐Grandparent ☐ Foster Parent
☐ Other, (please specify): ____

Source: Sarkar, U., Schillinger, D., Lopez, A., & Sudore, R. (2010).

Appendix E

IRB Approval Letters and Informed Consent Agreement



UNIVERSITY of VIRGINIA
OFFICE OF THE VICE PRESIDENT FOR RESEARCH
INSTITUTIONAL REVIEW BOARD FOR THE SOCIAL AND BEHAVIORAL SCIENCES

In reply, please refer to: Project # 2014-0315-00

October 7, 2014

Jennifer Hutchinson
Christine Kennedy
Academic Divisions
1050 Woodbridge Ct.
Forest, VA 24551

Dear Jennifer Hutchinson and Christine Kennedy:

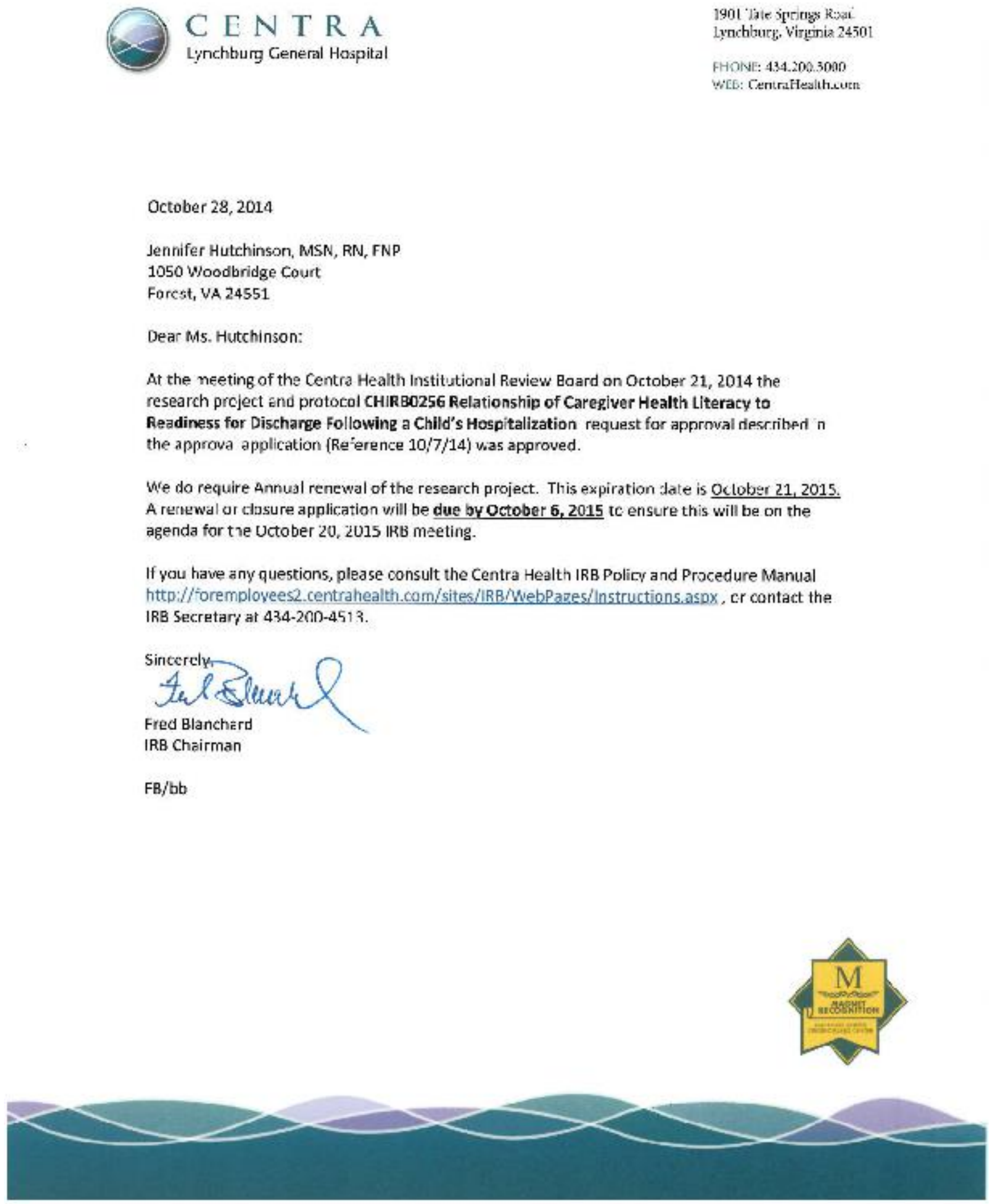
The Institutional Review Board for the Behavioral Sciences has approved your research project entitled "Relationship of Caregiver Health Literacy to Readiness for Discharge Following a Child's Hospitalization." You may proceed with this study. Please use the surface-mailed Consent Form as the master for copying forms for participants.

This project # 2014-0315-00 has been approved for the period October 7, 2014 to October 6, 2015. If the study continues beyond the approval period, you will need to submit a continuation request to the Review Board. If you make changes in the study, you will need to notify the Board of the changes.

Sincerely,

Tonya R. Moon, Ph.D.
Chair, Institutional Review Board for the Social and Behavioral Sciences

One Morton Drive, Suite 500 • Charlottesville, VA 22903
P.O. Box 800392 • Charlottesville, VA 22908-0392
Phone: 434-924-5999 • Fax: 434-924-1992
www.virginia.edu/vpr/irb/sbs.html



CENTRA
Lynchburg General Hospital

1901 Tate Springs Road
Lynchburg, Virginia 24501

PHONE: 434.200.3000
WEB: CentraHealth.com

October 28, 2014

Jennifer Hutchinson, MSN, RN, FNP
1050 Woodbridge Court
Forest, VA 24551

Dear Ms. Hutchinson:

At the meeting of the Centra Health Institutional Review Board on October 21, 2014 the research project and protocol **CHIRB0256 Relationship of Caregiver Health Literacy to Readiness for Discharge Following a Child's Hospitalization** request for approval described in the approval application (Reference 10/7/14) was approved.

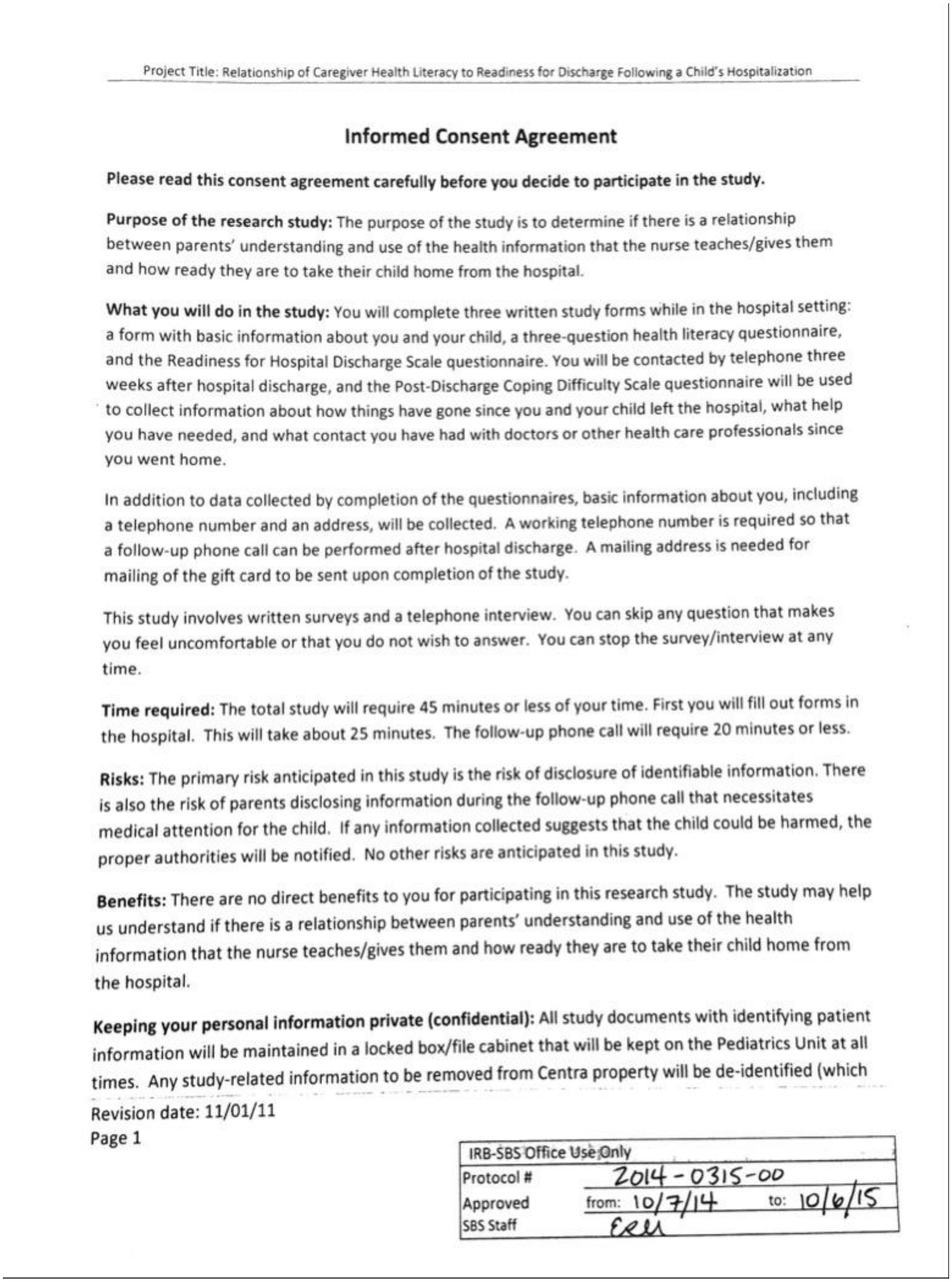
We do require Annual renewal of the research project. This expiration date is October 21, 2015. A renewal or closure application will be **due by October 6, 2015** to ensure this will be on the agenda for the October 20, 2015 IRB meeting.

If you have any questions, please consult the Centra Health IRB Policy and Procedure Manual http://foremployees2.centrahealth.com/sites/IRB/WebPages/Instructions.aspx , or contact the IRB Secretary at 434-200-4513.

Sincerely,

Fred Blanchard
IRB Chairman

FB/bb



Project Title: Relationship of Caregiver Health Literacy to Readiness for Discharge Following a Child's Hospitalization

Informed Consent Agreement

Please read this consent agreement carefully before you decide to participate in the study.

Purpose of the research study: The purpose of the study is to determine if there is a relationship between parents' understanding and use of the health information that the nurse teaches/gives them and how ready they are to take their child home from the hospital.

What you will do in the study: You will complete three written study forms while in the hospital setting: a form with basic information about you and your child, a three-question health literacy questionnaire, and the Readiness for Hospital Discharge Scale questionnaire. You will be contacted by telephone three weeks after hospital discharge, and the Post-Discharge Coping Difficulty Scale questionnaire will be used to collect information about how things have gone since you and your child left the hospital, what help you have needed, and what contact you have had with doctors or other health care professionals since you went home.

In addition to data collected by completion of the questionnaires, basic information about you, including a telephone number and an address, will be collected. A working telephone number is required so that a follow-up phone call can be performed after hospital discharge. A mailing address is needed for mailing of the gift card to be sent upon completion of the study.

This study involves written surveys and a telephone interview. You can skip any question that makes you feel uncomfortable or that you do not wish to answer. You can stop the survey/interview at any time.

Time required: The total study will require 45 minutes or less of your time. First you will fill out forms in the hospital. This will take about 25 minutes. The follow-up phone call will require 20 minutes or less.

Risks: The primary risk anticipated in this study is the risk of disclosure of identifiable information. There is also the risk of parents disclosing information during the follow-up phone call that necessitates medical attention for the child. If any information collected suggests that the child could be harmed, the proper authorities will be notified. No other risks are anticipated in this study.

Benefits: There are no direct benefits to you for participating in this research study. The study may help us understand if there is a relationship between parents' understanding and use of the health information that the nurse teaches/gives them and how ready they are to take their child home from the hospital.

Keeping your personal information private (confidential): All study documents with identifying patient information will be maintained in a locked box/file cabinet that will be kept on the Pediatrics Unit at all times. Any study-related information to be removed from Centra property will be de-identified (which

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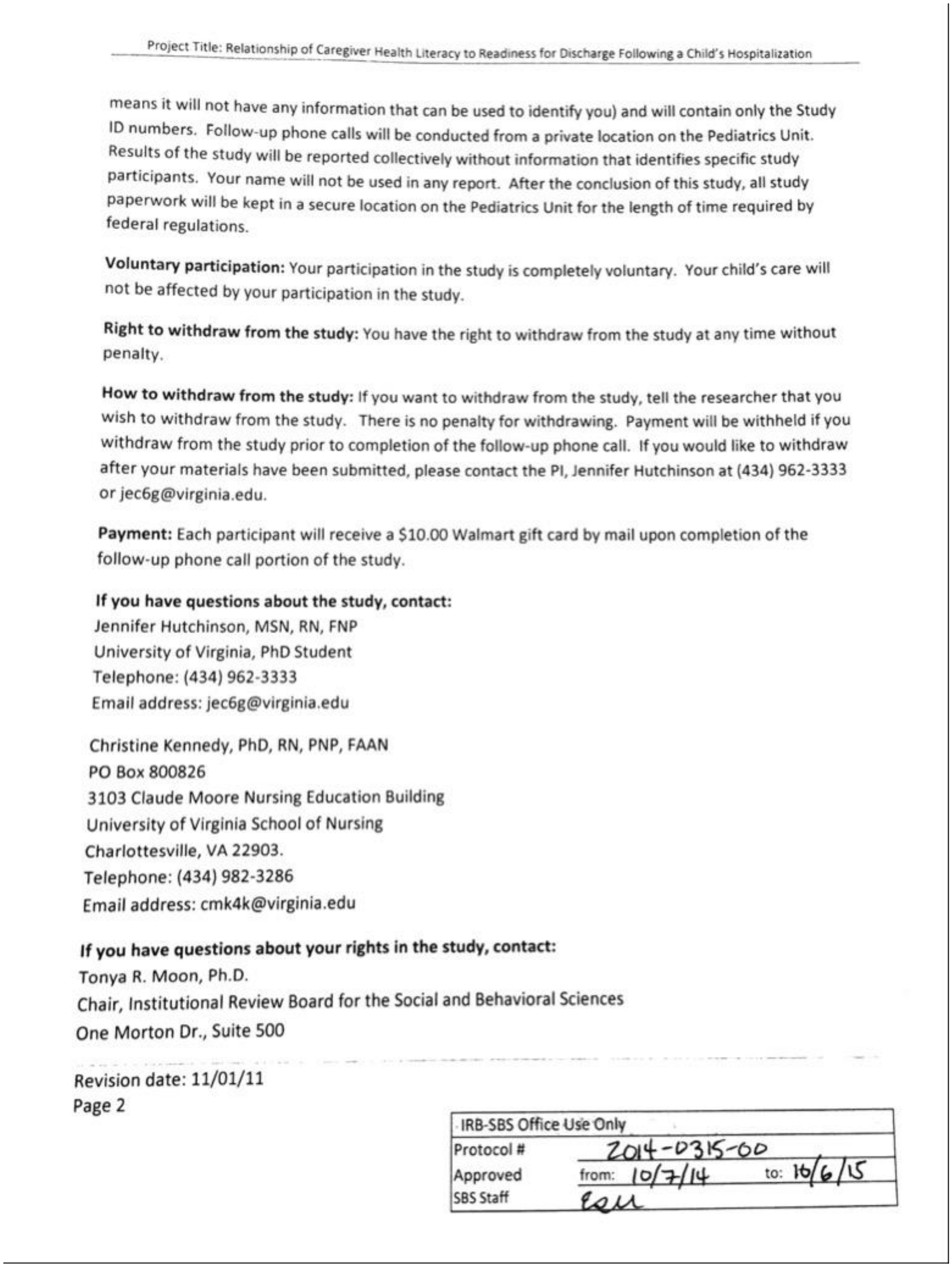
Approved	from: 10/7/14	to: 10/6/15
SBS Staff		



Project Title: Relationship of Caregiver Health Literacy to Readiness for Discharge Following a Child's Hospitalization

means it will not have any information that can be used to identify you) and will contain only the Study ID numbers. Follow-up phone calls will be conducted from a private location on the Pediatrics Unit. Results of the study will be reported collectively without information that identifies specific study participants. Your name will not be used in any report. After the conclusion of this study, all study paperwork will be kept in a secure location on the Pediatrics Unit for the length of time required by federal regulations.

Voluntary participation: Your participation in the study is completely voluntary. Your child's care will not be affected by your participation in the study.

Right to withdraw from the study: You have the right to withdraw from the study at any time without penalty.

How to withdraw from the study: If you want to withdraw from the study, tell the researcher that you wish to withdraw from the study. There is no penalty for withdrawing. Payment will be withheld if you withdraw from the study prior to completion of the follow-up phone call. If you would like to withdraw after your materials have been submitted, please contact the PI, Jennifer Hutchinson at (434) 962-3333 or jec6g@virginia.edu.

Payment: Each participant will receive a $10.00 Walmart gift card by mail upon completion of the follow-up phone call portion of the study.

If you have questions about the study, contact:

Jennifer Hutchinson, MSN, RN, FNP
University of Virginia, PhD Student
Telephone: (434) 962-3333
Email address: jec6g@virginia.edu

Christine Kennedy, PhD, RN, PNP, FAAN
PO Box 800826
3103 Claude Moore Nursing Education Building
University of Virginia School of Nursing
Charlottesville, VA 22903.
Telephone: (434) 982-3286
Email address: cmk4k@virginia.edu

If you have questions about your rights in the study, contact:

Tonya R. Moon, Ph.D.
Chair, Institutional Review Board for the Social and Behavioral Sciences
One Morton Dr., Suite 500

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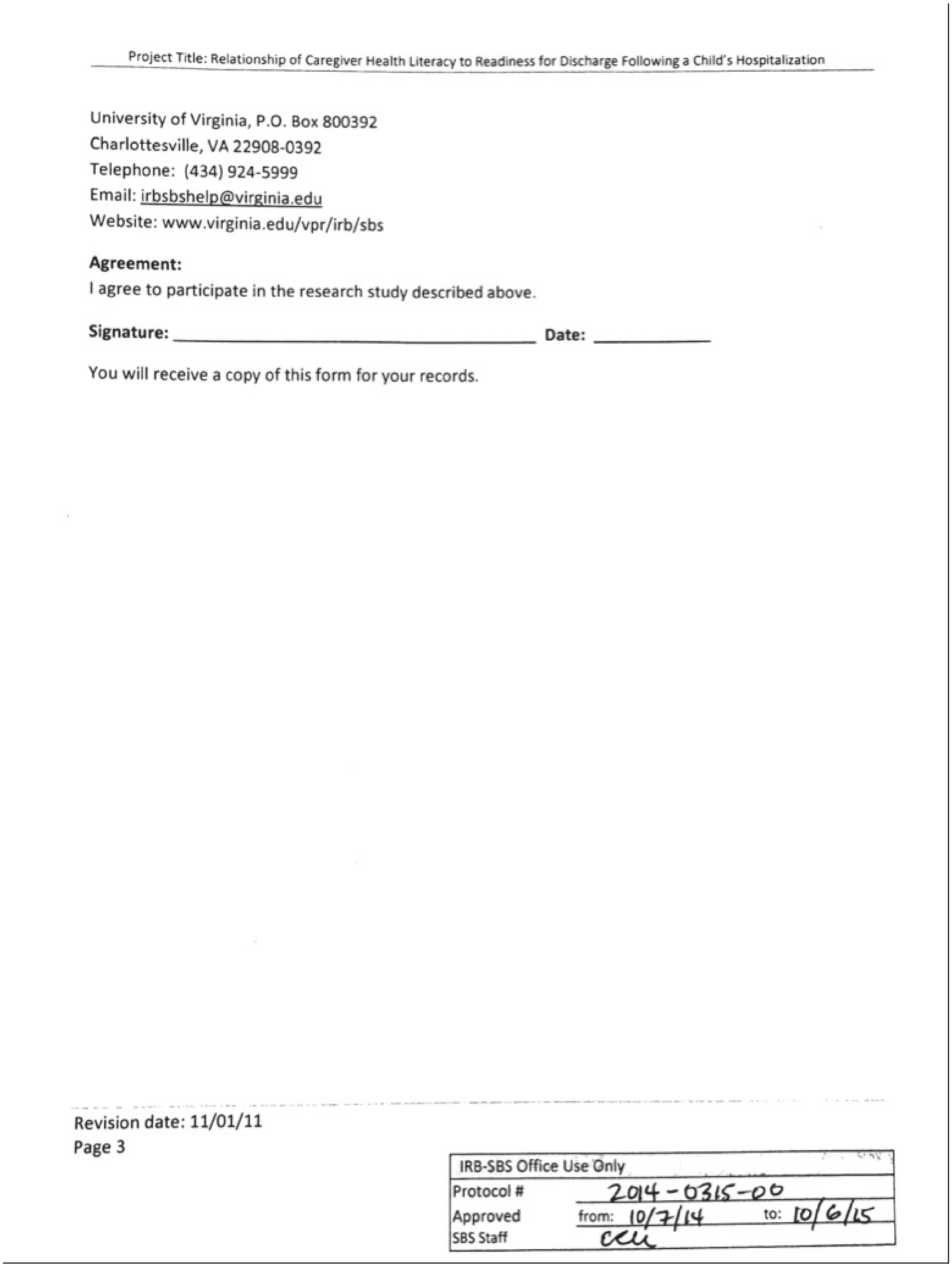

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University of Virginia, P.O. Box 800392
Charlottesville, VA 22908-0392
Telephone: (434) 924-5999
Email: irbsbshelp@virginia.edu
Website: www.virginia.edu/vpr/irb/sbs

Agreement:

I agree to participate in the research study described above.

Signature: ____ **Date:** ____________

You will receive a copy of this form for your records.

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SBS Staff	ccu	