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Sandy Anhai Ramirez Sanchez

2018

Hispanic Parent/Caregiver Health Literacy: Examining Effect on Pediatric Emergency
Department Utilization

A Dissertation Presented to
The Faculty of the Doctor of Social Work Program of
Kutztown University/Millersville University of Pennsylvania

In Partial Fulfillment
Of the Requirements for the Degree Doctor of Social Work

Sandy Anhai Ramirez Sanchez

30/March, 2018

ABSTRACT OF THE DISSERTATION

Hispanic Parent/Caregiver Health Literacy: Examining Effect on Pediatric Emergency

Department Utilization

By

Sandy Anhai Ramirez Sanchez

Kutztown University| Millersville University, 2018

Kutztown, Pennsylvania

Directed by Dr. David H. Johnson, PhD

This study aimed to explore Hispanic parent/caregiver health literacy and emergency department (ED) utilization for children ages birth to 10 years of age from a single outpatient pediatric primary care office in Wilmington, Delaware. English language proficiency (ELP) was measured to determine whether ELP was a moderating variable for ED utilization in children of Hispanic parents/caregivers. The following research question was explored in this study: “*Are there significant differences between levels of health literacy and emergency department utilization rates when controlling for level of English language proficiency in Hispanic parents/caregivers?*” The research question was guided by the following hypothesis: “*Hispanic parents/caregivers with higher levels of health literacy utilize emergency department services at lower rates when controlling for levels of English language proficiency.*”

Signature of Investigator _____ Date _____

Dedication

Gracias a Dios y la Virgen de Guadalupe.

Para mi querido esposo, Fernando, y la luz de mis ojos, Jimena. Los amo. Mis padres, Andrea y
Juan Martin, por su apoyo y amor.

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Chapter 1

Introduction

Significant political, social, and economic attention has been placed on the health care system across a range of topics including *inter alia* access, costs, outcomes, quality, and disparities. Embedded within these major “talking points” of health care is the concept of health literacy, especially low health literacy, and how this skill, or lack thereof, directly influences multiple factors that interface within the health care system. The U.S. Department of Health and Human Services (2011) defines health literacy as “the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions” (p. ES-1). Low health literacy is found in all age groups and ethnicities, it disproportionately affects certain vulnerable populations such as the elderly, those in poverty, Hispanics, and individuals without a high school diploma (Liechty, 2011). The U.S. Department of Health and Human Services (2011) further identified those that spoke another language other than English before starting school as a vulnerable population with higher rates of low health literacy. Low health literacy and health care reform are interconnected factors linked to increased use of emergency room services, decreased use of preventative medical services, increased hospitalizations, increased medication errors, and poor health outcomes that burden the health care system (U.S. Department of Health and Human Services, 2011).

Health literacy is a complex skill composed primarily of four interconnected areas: numeracy skills, reading and writing skills, cultural and conceptual knowledge, and speaking and listening skills (Wallace, 2010). Within the context of accessing and navigating the health care system, health literacy is an important skill and, for some, a major barrier. Systemically, the issue of health literacy affects all levels of care within the health care system and low health literacy is

found to be a strong predictor of health outcomes (Ownby, Acevedo, Waldrop-Valverde, Jacobs, & Caballero, 2014; Rojas-Guyler, Britigan, Murnan, King, & Vaughn, 2013). Furthermore, the issue of low health literacy is recognized as a systemic issue versus an individual deficit given the complexity of understanding and navigating the health care system (Koh, Berwick, Clancy, Baur, Brach, Harris, & Zerhusen, 2012; Nielsen-Bohlman, Panzer, & Kindig, 2004).

In the United States, low health literacy affects approximately 36 percent of adults (U.S. Department of Health and Human Services, 2011). Vernon, Trujillo, Rosenbaum, and DeBuono (2007) estimate the cost of low health literacy to be between \$106-\$238 billion dollars annually. Health literacy has evolved into a major concern as the health care landscape transformed to meet the needs of patients. Prior to the 1960s, the primary health problem in the United States was infectious diseases; post 1960s, this shifted to chronic diseases that are typically developed from an unhealthy lifestyle (Wodarski, 2014). The era of preventative medicine flourished to avert and address chronic medical issues, improve quality of life, and control health costs (Wodarski, 2014). Given the growing cost of health care and the limited resources within the health care system, the connection between health literacy and the utilization of emergency medical services in adult medicine is well established in the literature but gaps remain for the pediatric population (Morrison, Myrvik, Brousseau, Hoffman, & Stanley, 2013; Morrison, Schapira, Gorelick, Hoffmann, & Brousseau, 2014).

The scholarly literature surrounding health literacy is rich and diverse, but the social work profession has paid far less attention than other fields to this important topic in terms of research, advocacy and policy development efforts. This is despite the strong link between low health literacy and poor health outcomes and the disproportionately high impact of low health literacy on certain vulnerable populations (Liechty, 2011; Wallace, 2010). As social workers

become increasingly present in multidisciplinary teams that respond to patients' and families' complex medical and social issues, opportunities are available for the social work profession to contribute to the body of knowledge surrounding health literacy through research, policy development, and interdisciplinary collaborations. Examining parent/caregiver health literacy within the Hispanic community is vital given the projected increase in the Hispanic population in the United States from 17% of the total US population in 2014 to 29% by 2060 (US Census Bureau, 2015). This rapid increase in the Hispanic population, one that has been identified as having lower rates of health literacy compared to other ethnic/racial groups in the United States, presents an opportunity for research to improve on the current understanding of Hispanic parent/caregiver health literacy, develop appropriate and effective interventions, and measure the potential effects of low health literacy on the health of Hispanic children (Connelly & Turner, 2017; Betz, Ruccione, Meeske, Smith, & Chang, 2008). In an effort to contribute to the understanding of Hispanic parent/caregiver health literacy, this study aimed to explore the following research question: *“Are there significant differences between levels of health literacy and emergency department utilization rates when controlling for level of English language proficiency in Hispanic parents/caregivers?”* The research question was guided by the following hypothesis: *“Hispanic parents/caregivers with higher levels of health literacy utilize emergency department services at lower rates when controlling for levels of English language proficiency.”*

Chapter 2

Health literacy from a broader perspective

Health literacy research is extensive and continues to grow as the health care system expands, grows in complexity, advances in technology, and serves an ever-growing diverse patient population. Health literacy research typically examines the relationships between health literacy and a vast array of areas including medical conditions, patient behavior (information seeking, sources of information, compliance with treatment plans), the use of or development of tools to measure health literacy, utilization of health care resources (emergency department, primary care, preventative care), cost, health outcomes, disparities, health management skills, communication skills, health literacy impact on community health, parental/caregiver health literacy, adolescent health literacy and variations in levels of health literacy within minority groups, and many more areas. Although the definition of health literacy presented by the U.S. Department of Health and Human Services is most commonly cited in scholarly research articles, health literacy research continues to debate the very definition of health literacy (Berkman, Davis, & McCormack, 2010; Navarro-Rubio, Rudd, Rosenfeld, & Arrighi, 2016; Sorensen, Van den Broucke, Fullam, Doyle, Pelikan, Slonska, & Brand, 2012). Health literacy can be viewed as an individual skill, but as the demands of the health care system grow and technology evolves, the patient assumes greater responsibility through self-management tasks. These growing demands on consumers of health care services lead many researchers to argue that health literacy is dynamic and efforts to define and measure health literacy must take a broader perspective that evolves with the health care system and the changing demands on patients (McCormack, Thomas, Lewis, & Rudd, 2017; Pawlak, 2005; Zarcadoolas, Pleasant, & Greer, 2005). Scholarly literature has commonly cited and consistently agreed that age, socioeconomic status, level of

education, race/ethnicity, culture, and linguistic differences affect health literacy (Benjamin, 2010; Koskan, Friedman, & Hilfinger Messias, 2010; Wynia & Osborn, 2010). This range of research illustrates the complexity and diversity of health literacy research within the health care system. Table 1 summarizes the literature to be examined in this paper.

Table 1. Health Literacy (HL) Research Articles

Author(s)	Date of Publication	Methodology	Design	Population Studied	“N”
Aharon et al. (2017)	2017	Survey, HLQ	Cross sectional survey	Parents of children 3-4 years of age	731
Baker et al. (1996)	June 1996	REALM	Focus groups and individual interviews	Adults in two urban public hospitals	60
Bathory et al. (2016)	August 2016	Interview, survey, and STOFHLA	Quantitative	Hispanic caregivers of infants	557
Bishop et al. (2016)	May 2016	3 screening measures, STOFHLA (English and Spanish) and survey	Randomized sample	English and Spanish speaking adults from a community research registry in Dallas, TX	324-English speaking 314-Spanish speaking
Boyas (2013)	2013	Questionnaire, seven item screener	Nonprobability sample	Hispanics in various Arkansas communities	123
Brigham et al. (2016)	2016	Survey, WAMP	Convenience sample, quantitative	Parents with children (4-12 years of age) that have asthma	176
Britigan et al. (2009)	January 6, 2009	Semi-structured interviews, BAS, S-TOFHLA,	Qualitative	Hispanic adults in two southwest Ohio counties	52
Ciampa et al. (2013)	2013	SASH, STOFHLA, WRAT-3,	Convenience sample, quantitative	Hispanic caregivers of	184

		PHLAT Spanish		children <30 months	
DeWalt et al. (2007)	2007	REALM, questionnaire	Retrospective cohort study	Parents and children 3 to 12 years old	150
Dunn-Navarra et al. (2012)	2012	S-TOFHLA and NVS	Descriptive survey	Hispanic parents	154
Hahn et al. (2014)	2014	Talking touchscreen questionnaires	Convenience sample	English and Spanish speaking (Hispanic) adults with type 2 diabetes	English speaking adults=146 Spanish speaking adults=149
Hampers, et al., (1999)	1999	Review of medical records	Prospective cohort study	Parents who presented to the pediatric ED	2,467
Harrington et al. (2015)	2015	ACQ, TOFHL	Cross sectional study	Children 6-12 years old with asthma and their parents	281
Harris et al. (2017)	2017	NVS, survey	Cross-sectional analysis of a randomized controlled experiment	Hispanic parents of children <8 years old	1,126
Heerman et al., (2014)	2014	S-TOFHL, survey	Cross-sectional analysis, randomized trial	English and Spanish speaking caregivers	844
Heinrich (2012)	2012	NVS, demographic questionnaire	Descriptive, cross-sectional design	Adult diabetic patients in primary care	54
Herman et al. (2010)	2010	Survey, health book training	Randomized placebo control study	Low-income parents of Head Start children	9,240
Hom et al. (2012)	2012	Survey, REALD-30	Observational cohort	First time pregnant women	119
Hoover et al., (2012)	2012	TOFHLA, AQ-P and demographic questionnaire	Descriptive, correlation design	Parents/caregivers for asthmatic children	58

Jimenez et al. (2013)	2013	NVS, semi-structured interviews	Qualitative: grounded theory	Parents/caregivers with children referred to early intervention services	44
Kern et al., (2015)	2015	Demographic questionnaire, TOFHLA and S-TOFHLA	Cross-sectional study	Hispanic and non-Hispanic parents	88
Kumar et al. (2010)	2010	Demographic questionnaire, S-TOFHLA, WRAT-3, survey, PHLAT, and PHLAT-10	Cross-sectional study, convenience sample	Parents/caregivers of infants <13 months	182
Kutner et al. (2006)	September 2006	Questionnaire, health literacy “tasks” in an assessment booklet	Quantitative	Adults 16 years and older, English speaking only	19,000
Lee et al. (2006)	2006	SAHLSA, REALM	Psychometric assessment of the SAHLSA	Spanish and English speaking adults	Spanish speaking adults=201 English speaking adults=202
Leyva et al. (2005)	January 2005	DIS, 5 question test	Cross-sectional survey	Spanish-speaking Hispanic parents with limited English proficiency	100
Lo et al. (2006)	2006	Survey, TOFHLA	Anonymous cross-sectional survey	English-speaking parents	326
May et al. (2017)	2017	NVS, interviews	Mixed methods	Parents of non-urgent patients seen in the ED	50
Moon et al., (1998)	1998	REALM, survey	Prospective cohort	Parents/caregivers of children seeking acute care	633

Morrison et al., (2014)	May/June 2014	NVS	Cross-sectional study	Caregivers using a pediatric ED	503
Morrison et al. (2014)	September 2014	NVS	Cross-sectional study	Parents/caregivers of children using the ED for febrile illness	299
Morrison et al. (2014)	2014	S-TOFHL, NVS, record reviews	Planned analysis	English or Spanish speaking parents	501
Neuman et al. (2014)	2014	Secondary data analysis	Retrospective study	ED use in children 0-18 years old in 25 states	1,896,547
Parikh et al. (1996)	1996	TOFHL, survey	Cross sectional	Adult patients in a public hospital in Atlanta, GA	202
Pati et al. (2011)	2011	S-TOFHLA, survey,	Longitudinal prospective cohort study	Medicaid-eligible mothers and their infants	506
Porter et al. (2011)	2011	TOFHLA	Randomized controlled trail	Parents of children with ADHD	180
Rojas-Guyler et al. (2013)	Fall 2013	Semi-structured interviews, BAS, REALM-SF, S-TOFHLA	Mixed methods, intercept sampling method	Hispanic immigrants in Cincinnati	214
Ryan et al. (2008)	2008	NVS	Controlled trial	Adults in 20 primary care offices in South Florida	289
Sanders et al. (2004)	2004	S-TOFHL, 7 screening questions	Cross sectional	Parents of children 12-24 months	163
Sanders et al. (2007)	2007	S-TOFHL (English or Spanish)	Cross sectional	English or Spanish speaking parents presenting to the pediatric	290

				ED with children 12 months to 12 years old	
Sentell et al. (2012)	2012	Random digit dial telephone survey (CHIS public-use data file)	Quantitative	Asian, Latino, Korean, Vietnamese, and White adults in California	48,427
Shone et al., (2009)	2009	REALM, demographic questionnaire, PACQLQ, home interviews	Quantitative	Parents of school-aged urban children with persistent asthma in Rochester, NY	499
Singh et al. (2015)	2015	Questionnaire, SAHL, NVS	Cross-sectional design, convenience sample	Spanish-speaking adults in Columbus, OH	151
Sturm et al., (2010)	2010	Survey and secondary data analysis	Retrospective	Pediatric primary care offices	33
Weiss et al., (2005)	2005	TOFHLA	Cross sectional	English and Spanish speaking primary care patients	500
Wood et al. (2010)	2010	Asthma questionnaire	Cross sectional	African American parents/guardians	196
Yee et al. (2014)	2014	In-depth interviews, survey, REALM-7, and Schwartz numeracy scale	Qualitative	Chicago women (African American and Hispanic)	30
Yin et al. (2007)	July 2007	Interview, TOFHLA,	Mixed methods, Cross-sectional analysis	Parents/caregivers of pediatric patients (30 days to 8 years old) in an urban pediatric ED	292

Yin et al., (2009)	November 2009	NADL	Cross-sectional study	Parents who participated in the NADL	6100
Yin et al., (2011)	January 2011	NVS	Experimental	Parents/caregivers of children at an urban pediatric clinic	299
Yin et al., (2012)	January 2012	PHLAT-10, S-TOFHLA, WRAT-3,	Cross-sectional analysis	Spanish speaking Parents/caregivers of children <30 months	176
Yin et al., (2016)	2016	NVS, survey	Controlled experiment	English and Spanish speaking parents of children 8 years of age or younger	2,110

Several major governmental and government sponsored studies have examined health literacy from a broader perspective and have served as justification for ongoing research in health literacy.

In 2003, the National Centers for Educational Statistics (NCES) conducted a comprehensive National Assessment of Adult Literacy (NAAL) to measure the English health literacy of America’s adults aged 16 and older. To date, this is the most wide-ranging assessment conducted in the United States that specifically looked at measuring health literacy in English-speaking adults through the use of health literacy scales and tasks that mimic real life activities requiring health literacy skills (Kutner, Greenberg, Jin, & Paulsen, 2006). Health literacy was measured as falling within the following ranges: proficient, intermediate, basic, and below basic (Kutner et al., 2006). Overall, the survey found that of the 19,000 participants, a majority, 53%, had intermediate health literacy while 22% had basic, 14% had below basic, and 12% had

proficient health literacy (Kutner et al., 2006). The lowest health literacy was found within the Hispanic adults when compared to all other ethnic groups (Kutner et al., 2006). Women were identified as having, on average, higher health literacy when compared to men (Kutner et al., 2006). However, health literacy remains a barrier for many women, especially minority women. A mixed method study found that health literacy can affect women's health as it directly influences a woman's knowledge about and proper utilization of contraception (Yee & Simon, 2014).

The NAAL further found that “adults who spoke only English before starting school had higher average health literacy than adults who spoke other languages alone or other languages and English” (Kutner et al., 2006, p. v). Language dominance has proven to be a key factor in determining health literacy proficiency. Hahn, Kallen, Jacobs, Ganschow, Garcia, and Burns (2014) found that English speaking adults (n=146) had on average higher levels of health literacy when compared to Spanish speaking adults (n=149) with type 2 diabetes. Adults without insurance coverage and those with insurance coverage from Medicaid or Medicare had lower health literacy on average compared to adults that had private insurance from a family member, the military, an employer, or insurance that they had purchased on their own (Kutner et al., 2006). Within those adults that reported Medicare or Medicaid as their primary source of medical insurance, 30% of Medicaid and 27% of Medicare adults had below basic health literacy (Kutner et al., 2006). To date, the focus of the NAAL study on health literacy has not been repeated.

The Agency for Healthcare Research and Quality (AHRQ), within the U.S. Department of Health and Human Services, published a report in 2011 that summarized a systematic review of health literacy interventions and outcomes (Berkman, Sheridan, Donahue, Halpern, Viera,

Crotty, Holland, Brasure, Lohr, Harden, Tant, Wallace, & Viswanathan, 2011). Overall, the AHRQ (Berkman et al., 2011) report found that:

Differences in health literacy level were consistently associated with increased hospitalizations, greater emergency use, lower use of mammography, lower receipt of influenza vaccine, poorer ability to demonstrate taking medications appropriately, poorer ability to interpret labels and health messages, and, among seniors, poorer overall health status and high mortality. (p. V).

Justifications for the AHRQ report came from findings that associate low health literacy rates with minority groups, the elderly, those without a high school diploma, those in poverty, and with individuals that spoke another language that was not English before starting school (Berkman et al., 2011).

In a separate document, the U.S. Department of Health and Human Services issued the National Action Plan to Improve Health Literacy (NAPIHL) in 2010 and outlined seven broad goals to address health literacy. The plan advocated for integration of science and health information throughout the education curriculum of children to target developmentally appropriate health literacy knowledge, increased research in developing, applying, and evaluating health literacy interventions, and the proliferation of evidence-based health literacy interventions. The broad goals outlined in the NAPIHL called upon organizations and professions, without specifically stating which professions, to take action to address health literacy. The report further emphasized the need for systemic collaboration and coordination to address health literacy in an effort to reduce costs, improve access, quality, safety, health outcomes, and quality of life (U.S. Department of Health and Human Services, 2010).

Hispanic Parent/Caregiver and Health Literacy

The health literacy of Hispanic parents/caregivers plays a role in how medical information is understood and applied when caring for children, with some research arguing that parental/caregiver health literacy has an impact on a child's health prior to birth with the mother's self-care decisions (Connelly & Turner, 2017; Hom, Lee, Divaris, Baker, & Vann, 2012; Nield, 2008). In most cases, the caregiver of a child is the mediator between the health care system and the child's health care needs (Abrams, Klass, & Benard, 2009). The complexities of responding to a child's medical needs and maintaining a child's health for optimal growth and development can be daunting for caregivers. Low health literacy in caregivers has been associated with poor health outcomes for children, especially when parents have less than a high school diploma, are born outside the United States, and have limited English proficiency (DeWalt & Hink, 2009; Leyva, Sharif, & Ozuah, 2005; Sanders, Thompson, & Wilkinson, 2007; Yin, Johnson, Mendelsohn, Abrams, Sanders, & Dreyer, 2009). In general, studies have found Hispanic adults are disproportionately affected by low health literacy (Betz, Ruccione, Meeske, Smith, & Chang, 2008; Kim & Xie, 2017; Kutner, Greenberg, Jin, & Paulsen, 2006; Liechty, 2011). Parental/caregiver health literacy has been shown to affect how parents exchange information between the parent/caregiver and medical providers related to disease management and the reporting of symptoms (Porter, Guo, Bacic, & Chan, 2011). Younger parents are found to have low health literacy, especially when accompanied by less formal education (Moon, Cheng, Patel, Baumhaft, & Scheidt, 1998; Sanders, Federico, Klass, Abrams, & Dreyer, 2009; Yin et al., 2009). Variables such as culture and degree of acculturation further influence the health literacy of Hispanic caregivers (Ciampa, White, Perrin, Yin, Sanders, Gayle, & Rothman, 2013; Shaw, Huebner, Armin, Orzech, & Vivian, 2009).

The diversity of patients served in the health care system validates the growing number of tools developed to measure health literacy, and variations on what each tool measures speak to the on-going debate of what constitutes health literacy and how it should be measured (Ownby, Acevedo, Waldrop-Valverde, Jacobs, & Caballero, 2014). Measuring health literacy and developing tools to measure health literacy in Hispanic caregivers has continued to be the main focus of several research articles. Research that specifically looks to measure the level of health literacy in adults have commonly used validated scales such as the Test of Functional Health Literacy in Adults (TOFHLA) available in both English and Spanish, The Rapid Estimate of Adult Literacy in Medicine (REALM), the Medical Term Recognition Test (METER), and the Newest Vital Sign (NVS) in both English and Spanish (Heinrich, 2012). The Spanish version of the TOFHLA, the S-TOFHLA, and the NVS were tested with caregivers (N=501) of children to compare the performance of both validated tools when used with caregivers (Morrison, Schapira, Hoffmann, & Brousseau, 2014). The NVS was shown to not only be efficient – it takes about 3 minutes to administer – but worked well in measuring the health literacy of young (median age of 32) caregivers in primary care settings and demonstrated predictive ability regarding emergency department utilization (Morrison et al., 2014). The NVS is available in both English and Spanish and has shown good reliability (Cronback $\alpha > 0.76$ in English and 0.69 in Spanish) (Weiss, Mays, Martz, Castro, DeWalt, Pignone, Mockbee, & Hale, 2005). The Parental Health Literacy Activities Test (PHLAT) was developed by Kumar, Sanders, Perrin, Lokker, Patterson, Gunn, Finkle, Franco, Choi, and Rothman (2010) as the first scale that specifically measures parental health literacy in English. The PHLAT was shown to have good reliability (Kuder-Richardson coefficient of reliability=0.76) and construct validity but is limited to parents with children from birth to 1 year of age (Kumar et al., 2010). Additional research by Yin, Sanders,

Rothman, Mendelsohn, Dreyer, White, Finkle, Prendes, and Perrin (2012) produced a Spanish version of the PHLAT given the need to address parental health literacy in the Hispanic community. The PHLAT-10 Spanish was shown to have good reliability (Kuder-Richardson coefficient of reliability=0.61) and content validity (Yin et al., 2012). Research by Kumar et al., (2010) with the PHLAT showed that higher scores on the PHLAT correlated with higher literacy skills, education level, and numeracy skills. Likewise, higher scores on the PHLAT-10 Spanish were correlated with higher literacy skills, educational level, and numeracy skills (Yin et al., 2012). Research in health literacy has further focused on developing shorter tools to measure health literacy in Hispanic adults. The Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA) is one of those tools specifically aimed at measuring health literacy in Hispanic adults over a shorter period of time (3-6 minutes) as opposed to 20 minutes for other validated tools, and can be implemented in pediatric primary care settings with adult parents/caregivers (Lee, Bender, Ruiz, & Cho, 2006).

Although there are multiple tools developed to measure health literacy, most are not commonly used in the health care system to help guide patient/provider communication due to time constraints that limit the ability to administer such tools (Bishop, Lee, Skinner, Jones, McCallister, & Tiro, 2016; McCune, Lee, & Pohl, 2016; Weiss, Mays, Martz, Castro, DeWalt, Pignone, Mockbee, & Hale, 2005). In response to time constraints in medical practice settings, research has shifted focus towards developing and testing screening questions (one to three questions) and developing shorter, valid and reliable screening tools to detect potential health literacy barriers that medical providers can use to guide and tailor patient communication (Sanders, Zacur, Haecker, & Klass, 2004; Singh, Scott-Coyne, & Wallace, 2015). Fear of embarrassing and shaming patients if approached with health literacy screening tools have

created the perception that patients will decline such screenings (Baker, Parker, Williams, Pitkin, Parikh, Coates, & Imara, 1996; Parikh, Parker, Nurss, Baker, & Williams, 1996). However, not all research has shown shame as inhibiting health literacy screenings. Research in South Florida with 20 diverse primary care practices (N=289) ranging from private to public practices and clinics found that 98.3% of research participants consented to a health literacy screening (Ryan, Leguen, Weiss, Albury, Jennings, Velez, & Salibi, 2008).

The health literacy of parents/caregivers with children that have a chronic health condition has yielded multiple research studies. Asthma is one of the most researched chronic health conditions, one where the health literacy of caregivers was measured along with short-term health outcomes for children with asthma. Few research articles have examined long-term health outcomes for children or intervention outcome for children in relation to caregiver health literacy (Abrams, Klass, & Benard, 2009; DeWalt & Hink, 2009; Rosas-Salazar, Apter, Canino, & Celedon, 2012). Brigham, Goldenberg, Stolfi, Mueller, and Forbis (2016) found that parental health literacy (N=176), using the NVS tool, in relation to the use of a written asthma management plan and a child's asthma control, was associated with a decreased ability to use a written asthma management plan. Other studies have found that parents' asthma knowledge and ability to properly manage the child's asthma is directly related to their level of health literacy (DeWalt, Dilling, Rosenthal, & Pignone, 2007; Elbash & Coustasse, 2016; Harrington, Zhang, Magruder, Bailey, & Gerald, 2015; Hoover, Pierce, Spencer, Britten, Neff-Smith, James, & Gueldner, 2012; Shone, Conn, Sanders, & Halterman, 2009). This is in part to the parents' need to understand written medical instructions, recognize signs and symptoms of asthma, properly administer medications, and apply all of this information appropriately for optimal management of asthma symptoms for improved health outcomes (Harrington et al., 2015). Yet research has

found mixed results in relation to poor health management of asthma in children and emergency department utilization. Dewalt et al. (2007) and Hoover et al. (2012) reported an increased number of reported emergency department visits of children with asthma when the child's parents have low health literacy. Shone et al. (2009) and Wood, Price, Dake, Telljohann, & Khuder (2010) reported no association between parental health literacy and emergency department utilization. Proposed explanations for these findings suggest that lower emergency department visits of children with asthma can be explained by available services and resources in the community and the parent/caregiver's knowledge and understanding of these services (Shone et al., 2009). Wood et al. (2010) only looked at African American children with asthma ages 5 to 12 years old and noted that lower emergency department utilization in the sample (N=196) could be associated to the one-on-one education the parent/caregiver received from the medical staff. Furthermore, data from the Wood et al. (2010) study came from asthmatic patients seen in specialty care (pediatric pulmonologists) and outpatient care (primary care pediatrician).

Several studies have explored the health literacy of Hispanic caregivers in the context of parental/caregiver health knowledge and behaviors that affect the growth and development of Hispanic children. Jimenez, Barg, Guevara, Gerdes, and Fiks (2013) is one of the few studies found to examine health literacy using a qualitative approach to explore the concepts of communication and action/behavior, both part of health literacy, as they relate to early intervention (EI) referrals. Jimenez et al. (2013) conducted 44 interviews with caregivers of children referred to EI and found that the children of caregivers with low health literacy had lower rates of EI evaluations and services. Hispanic parents/caregivers with less education were found to have limited health literacy specifically related to an upper respiratory infection (URI) and erroneously expected antibiotic treatment for an URI when this is typically not medically

needed (Dunn-Navarra, Stockwell, Meyer, & Larson, 2012). This relationship between limited health literacy and inadequate health knowledge related to proper antibiotic use in children directly affects health outcomes and provides opportunity for targeted education (Dunn-Navarra et al., 2012). One area in need of targeted education is that of common illnesses, as described above with the URI, and how to manage these conditions at home. Vaccination rates in children where health literacy was explored has yielded mixed results. A longitudinal prospective cohort study (N=506) found that the vaccination rates of infants between 3 and 7 months of age was not associated with the mother's health literacy (Pati, Feemster, Mohamad, Fiks, Grundmeier, & Cnaan, 2011). However, a cross-sectional survey (N=731) of parents found lower vaccination rates among parents with higher health literacy, education, and age (Aharon, Nehama, Rishpon, & Baron-Epel, 2017). Aharon et al. (2017) suggest these findings can be partially explained by the inability of many parents, even those with high health literacy, to differentiate between credible and incredible sources of vaccine information. Furthermore, parents with high health literacy have access to and actively pursue health information that may feed into pre-existing attitudes on vaccination and the recommended vaccination protocols (Aharon et al., 2017). Recent research explored the relationship between parental health literacy and a child's growth and development with attention focused on infant sleep. On average, one in four parents of young children report concerns for their child's sleep duration and regularity (Bathory, Tomopoulos, Rothman, Sanders, Perrin, Mendelsohn, Dreyer, Cerra, & Yin, 2016). Adequate sleep is critical for a child's development and lack of sleep or irregularity in sleep is linked to behavioral problems (Bathory et al., 2016). In a study of parents (N=557) regarding children's sleep environments, Bathory et al., (2016) found that parents with low health literacy were more than twice as likely to report that their young child had a TV in their bedroom when compared to

parents with adequate health literacy. Another area of health knowledge critical for parents is injury prevention. A cross-sectional analysis of English and Spanish speaking parents/caregivers (N=844) found that regardless of health literacy, many parents are non-adherent with all injury prevention guidelines (Heerman, Perrin, Yin, Sanders, Eden, Shintani, Coyne-Beasley, Bronaugh, Barkin, & Rothman, 2014). Yet when compared to parents with adequate health literacy, parents/caregivers with low health literacy had an increased odds of not following proper car seat position and fire safety guidelines (Heerman et al., 2014). Contrary to most health literacy research with Hispanic parents/caregivers, findings from a cross-sectional study (N=88) by Kern, Watts, Rychlik, and McColley (2015) of Hispanic and non-Hispanic parents/caregivers of children with cystic fibrosis found that 95% of the parents had adequate health literacy and health literacy was unlikely to affect health outcomes. However, the single site study had a relatively small sample size with young parents and researchers acknowledge that young adults are disproportionately affected by the ceiling effect of the Short Test of Functional Health Literacy in Adults (S-TOFHLA) as limitations that possibly explain the study's findings (Kern et al., 2015).

Limited English proficiency (LEP) and the health literacy of Hispanic adults, including parents, has been explored in several studies (Leyva, Sharif, & Ozuah, 2005; Rojas-Guyler, Britigan, Murnan, King, & Vaughn, 2013; Sentell & Braun, 2012). However, as with defining health literacy, how to define and measure LEP has recently received attention to reflecting the complexity and dynamic use of language in many Hispanic communities and other ethnic groups (Jacobson, Hund, & Soto Mas, 2016; McKee & Paasche-Orlow, 2012). LEP affected the ability of Hispanic caregivers to understand written medication instructions even when Spanish speaking caregivers were provided with medication instructions in their native language (Leyva

et al., 2005). A cross-sectional analysis of Hispanic caregivers (n=1126) with low health literacy and limited English proficiency were found to have higher rates of liquid medication dosing errors compared to caregivers with adequate health literacy and English proficiency (Harris, Dreyer, Mendelsohn, Bailey, Sanders, Wolf, Parker, Patel, Kim, Jimenez, Jacobson, Smith, & Yin, 2017). Hampers, Cha, Gutglass, Binns, and Krug (1999) looked at language barriers—specifically, parents/caregivers that did not speak English—in relation to resource utilization in a pediatric emergency department (N=2467). Of the total sample, 12% did not speak English and this language barrier was associated with both a higher number of diagnostic studies and longer emergency department visit times. McKee and Passche-Orlow (2012) conducted a search of the literature and found that although interconnected and typically targeting the same Hispanic population, research in health literacy and limited English proficiency have rarely collaborated. These missed opportunities for collaboration need to be explored as they harbor promising potential to help develop interventions that address the linguistic and health literacy deficits of a vulnerable population in need of skills to both comprehend and take action on health recommendations (McKee & Paasche-Orlow, 2012).

Research in parental health literacy and medication errors has grown as research explores the prevalence of medication errors and suggests possible interventions. Lo, Sharif, and Ozuah (2006) looked at rates of incorrect over-the-counter medication dosage in English speaking caregivers (N=326). This study was conducted in the same geographic area as the Hispanic caregivers from the previous Leyva et al., (2005) study and determined that 77% of the participants incorrectly dispensed medication (Lo et al., 2006). Of the 77% that incorrectly dispensed medication, the participants shared four major characteristics: lack of a high-school degree, parents were younger in age, were immigrants, and most reported never learning how to

use a medicine dropper (Lo et al., 2006). Adults with low health literacy that incorrectly measured liquid medication and used non-standardized dosing instruments like kitchen spoons were found to have low health literacy, especially lower reading comprehension skills, and lacked understanding of weight-based dosing for children (Yin, Dreyer, Foltin, van Schaick, & Mendelsohn, 2007). Similar findings were obtained from a controlled randomized experiment with English and Spanish speaking parents (n=2,110) found that parents with low health literacy were more likely to choose a non-standardized dosing tool to dispense pediatric liquid medication (Yin, Parker, Sanders, Dreyer, Mendelsohn, Bailey, Patel, Jimenez, Kim, Jacobson, Hedlund, Landa, Maness, Raythatha, McFadden, & Wolf, 2016). Furthermore, parents were found to choose non-standardized tools (for example: a kitchen spoon) to dispense pediatric liquid medication when the word teaspoon or the abbreviation of teaspoon, tsp, was used on the prescription label (Yin et al., 2016). A descriptive study of 200 nonprescription pediatric liquid medication (Yin, Parker, Wolf, Mendelsohn, Sanders, Vivar, Carney, Cerra, & Dreyer, 2012) found that a majority of dosing instructions are not provided with parental health literacy in mind. Findings from a randomized study concluded that parents/caregivers (N=299) from an urban hospital, where 77.9% of the sample had limited health literacy, who were provided with text-plus-pictogram instructions for dispensing acetaminophen to their child were less likely to make a medication error, 43.9%, compared to 59.0% who received text-only instructions (Yin, Mendelsohn, Fierman, van Schaick, Bazan, & Dreyer, 2011). Intervention suggestions include eliminating the use of teaspoon and tablespoon from medication labels and the development and testing of health literacy friendly medication labels for parents/caregivers (Yin et al., 2012; Yin et al. 2016).

At a broader level, the Centers for Medicare and Medicaid Services (CMS) have sought to reduce the nonurgent use of ED services as a way of reducing healthcare costs and improving access to appropriate care settings like primary care while collaborating with states, insurance companies, medical providers, and consumers (Mann, 2014). Compared to individuals that are insured by commercial/private health care, Medicaid beneficiaries have a two-fold higher rate of ED utilization (Mann, 2014). A bulletin issued by director Cindy Mann of CMS in 2014, reported on multiple efforts to reduce ED utilization due to the cost-saving results like those experienced by North Carolina who reduced ED utilization by implementing medical and health homes that reduced ED utilization by 16%. The 16% reduction in ED utilization was obtained by providing extended primary care hours, nurse advice phone line 24 hours a day/7 days per week, and same day appointments (Mann, 2014). North Carolina saved the Medicaid and Children's Health Insurance Program (CHIP) about \$135 million (Mann, 2014). CMS data show that two-thirds of ED visits occur after the typical business hours of 9am to 5pm and extending primary care services after business hours can potentially save the Medicaid program \$4.4 billion (Mann, 2014). However, research has found that cost-savings at the federal level will require significant resources at the primary care level (Neuman, Alpern, Hall, Kharbanda, Shah, Feedman, Aronson, Florin, Mistry, & Berry, 2014; Sturm, Hirsh, Lee, Massey, Weselman, & Simon, 2010). Individuals that use the ED 4 times per year or more are considered "super-utilizers" by CMS and make-up 4.5% to 8% of the total ED patients but account for 21%-28% of all the ED visits (Mann, 2014). The Healthcare Cost and Utilization Project (HCUP), from the Agency for Healthcare Research and Quality (AHRQ) within the U.S. Department of Health and Human Services, reported that 96% of the ED visits in 2010 for children resulted in children being treated and released, Medicaid was the largest primary payer, and twice as many ED visits for

children who lived in poor communities (Wier, Yu, Owens, & Washington, 2013). Children with chronic health conditions like asthma and diabetes that lack proper treatment and management of their conditions totaled \$417.2 million in ED services for asthma and \$89.4 million in ED services for diabetes in 2012 with Medicaid as the leading payer (Fingar & Washington, 2015). Within that same year, 58.1% of the asthma hospitalizations and 47.2% of the diabetes hospitalizations were classified as potentially preventable ED visits (Fingar & Washington, 2015).

Rising healthcare costs and limited health resources have prompted research into emergency department (ED) utilization of Hispanic parents/caregivers with limited health literacy and interventions to curtail unnecessary use of ED services. A cross-sectional study (N=503) of parents/caregivers who sought emergency department services in a Midwest children's hospital found that half of parents/caregivers who presented to the ED had low health literacy and had a greater number of prior ED visits, of which an increased number were non-urgent (Morrison, Schapira, Gorelick, Hoffmann, & Brousseau, 2014). Similar findings were reported by Morrison, Chanmugathas, Schapira, Gorelick, Hoffman, and Brousseau (2014), who found that two-thirds of parents/caregivers who presented to the ED for a child with a fever, considered a non-urgent ED visit, had low health literacy. A qualitative study conducted by May, Brousseau, Nelson, Flynn, Wolf, Lepley, and Morrison (2017) sought to explore how parents/caregivers (N=50) with low and adequate health literacy decide where to seek care, clinic or ED, for their child. Findings showed that parents with low health literacy overestimated the severity of the child's illness and used ED services to obtain quicker answers, whereas parents with adequate health literacy waited for an appointment at the clinic and sought reassurance (May et al., 2017). The lack of parent skills identified by May et al. (2017) was the focus of a

pilot health literacy intervention with parents/caregivers of children in Head Start through the use of a low literacy health book that parents/caregivers were trained on how to use and were allowed to keep (Herman & Jackson, 2010). Overall, 9,240 families participated in the intervention and research findings reported a 58% decrease in ED utilization (Herman et al., 2010).

The relationship between the degree of acculturation and level of health literacy was examined in research with the Hispanic population. Acculturation is “complex and multidimensional; however, it generally refers to the process whereby cultural learning takes place because of coming into contact with a new group or culture” (Boyas, 2013, p.33). Acculturation is an important aspect to examine given that health literacy needs to be studied within a cultural context that shapes “attitudes, beliefs, and values about health and health practices” to not only identify risk factors, but to identify and explore areas of opportunity for intervention (Boyas, 2013, p.33). Britigan, Murnan, and Rojas-Guyler (2009) found that those Hispanic participants they sampled had both low health literacy and a lower degree of acculturation. Similarly, in a study of Hispanic caregivers of infants under 30 months of age (N=184), Ciampa, White, Perrin, Yin, Sanders, Gayle, and Rothman (2013) found that lower levels of acculturation were associated with lower health literacy and reduced ability to accomplish health related skills for children. Increased levels of health literacy were found within Hispanic adults that had higher levels of education (beyond high school) and were more acculturated (Boyas, 2013). Yin, Jay, Maness, Zabar, and Kalet (2015) suggest taking a “universal precautions” approach to health literacy, where medical staff not only receive training to address patient’s health literacy but understand the impacts of the “health literacy environment” on patients. The medical environment is shaped by many interacting factors that in

turn influence how patients understand information, what actions are taken or not taken based upon the understood information, and whether patients ask questions (Yin et al., 2015).

Theoretical Framework

Human Capital Theory

The theory guiding this research, Human Capital Theory, was pioneered by American economists Theodore Schultz in 1961 and Gary Becker in 1964 as both economists collaborated in developing and promoting the theory (Becker, 1993; Hartog & Maassen van den Brink, 2007; Schultz, 1961). Schultz and Becker argued that human knowledge and skills are “capital” but not in the traditional sense like stocks/bonds, a bank account, or an electric power plant that produces revenue or other forms of output. Human capital is created when individuals invest in themselves, over long and short periods of time, through various activities. Education and training are two investments/activities that produce long term human capital gains as individuals pursue careers. Short term investments include food, shelter, and other basic necessities that meet the immediate needs of humans so they can continue to perform other long-term activities like completing a degree and pursuing a career. Although human capital theory began with an emphasis on education and training, it evolved into a general theory where multiple forms of human capital were taken into consideration.

Shifting the traditional view of capital from a tangible nonhuman item to humans initially received backlash as critics objected to reducing “man once again to a mere material component, to something akin to property. And for man to look upon himself as a capital good, even if it did not impair his freedom, may seem to debase him” (Schultz, 1961, p. 2). Yet, the theory persisted as it became apparent that humans invest in themselves in many ways and for many reasons. Connections developed between personal economic growth and the wider range of choices that

became available to those that invested in themselves, through education or other forms of knowledge and skills, to adapt and respond to the job market demands. Beyond the individual, human capital theory framed the understanding of how the earning power of individuals with a high school and/or a college education affected society and entire nations. Theodore Shultz (1961) summarized this new theoretical framework best when he wrote:

Knowledge and skills are in great part the product of investment and, combined with other human investment, predominantly account for the productive superiority of the technically advanced countries. To omit them in studying economic growth is like trying to explain Soviet ideology without Marx (p.3).

Human Capital Theory and Families

Gary Becker (1993) wrote extensively on the application of human capital theory to families and as a framework to understanding unemployment, inequality, discrimination and economic growth that affect families (Becker, 1971; Becker, 1991). Becker argued that the investments that parents make in their children through various activities such as reading, doing homework, and vaccinations are expenditures that parents put towards the human capital of their children that ultimately influence the future earnings of children when they are adults (Becker, 1993; Schiller, 2004). However, if the parent has low human capital or limited human capital (e.g., earning power, education, older age, multiple children, etc.), how much they can invest in the child's human capital becomes restricted as investments towards children can take away from the parent's own human capital. These human capital constraints are particularly apparent in low income families that typically have a parent or parents with less education, training, and disposable resources. The number of children a family has directly affects how much is invested in each child. Becker (1993) points to differences among ethnic groups in the United States

where groups that typically have smaller families, Cubans and Chinese, invest more in the child's human capital (e.g., education, training, etc.) while groups that typically have larger families, Mexicans and Puerto Ricans, have children with less human capital. One explanation for this, based on human capital theory, is that as parent's income rises they invest more in the human capital of their children but have fewer children. Hence, Becker (1993) questions the effects of government programs (e.g., Head Start, welfare, Women Infants and Children, etc.) when resources are redistributed but program outcomes are not strong, and argued that many program outcomes had a poor understanding of how a program affects parents' expenditures/investments in their children.

Human Capital Theory and Health

Hartog and Maassen van den Brink (2007) argue that education and health are interrelated and the two most significant human capital investments that individuals can make given the broad effect both have on productivity and economic benefits like income and resources. On a larger scale, nations that are better educated/trained and healthier are more productive and wealthier. The interconnections of education and health, as essential human capital, guide parenting in multiple ways: expectations and motivation for school work, the type of food consumed by the family/child, health related habits like exercise, and many more behaviors with both short and long term implications for human capital. Parents/caregivers that have higher levels of education are equipped with better knowledge to make healthier decisions for the optimal growth and development of their child or children that further adds to the human capital (future earnings) and health of the child as they grow (Hartog et al., 2007). Findings from Groot and Maassen van den Brink from 2006 (as cited in Hartog et al., 2007, p. 71) in the Netherlands, found that the mother's level of education has an effect on her daughter's health but

did not on her son's health. The father's level of education had no effect on the health of his children, either male or female, within the same study. However, Groot and Maassen van den Brink (2006) found that the country of origin of the parent did affect the health of the children. Overall, from a Human Capital Theory perspective, the direct investment made by parents towards the health and education of their child/children have short and long term implications on the health and future earnings of the child/children.

Human Capital Theory, Health Literacy, and English Language Proficiency

Health literacy can be viewed as knowledge and a set of skills that represents a form of human capital derived in part from formal education and endowments received from parents/caregivers. Obtaining, processing, and understanding medical information to make appropriate health decisions calls for investments of time, energy, and other resources to navigate and utilize the health care system for optimal health benefits. Likewise, English language proficiency (ELP) is a skill that represents a form of human capital for Hispanic parents/caregivers in the United States where English is the dominant language. ELP, especially for those parents/caregivers where English is not their first language, requires time, energy, and resources to develop. Limited ELP for many parents/caregivers can potentially hinder their ability to invest in the human capital of their children when it comes to navigating the health care system (for optimal growth and development) and the educational system (helping with homework, advocating for services, reading report cards).

Chapter 3

Methodology

Research Design

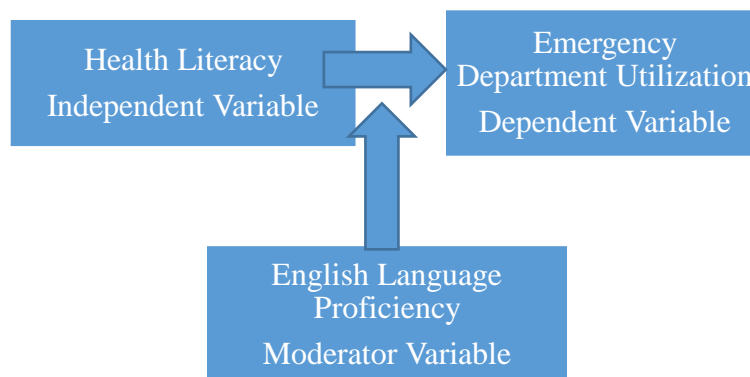
A cross-sectional study and secondary data analysis was utilized to explore the relationship between health literacy, English language proficiency (ELP), and emergency department (ED) utilization. The dependent variable (DV), emergency department (ED) utilization, was collected as secondary data from each pediatric patient's electronic medical record and the independent variable (IV), health literacy score, was collected at a specific point in time. Data collection consisted of a quantitative study where the researcher administered a one-time demographic questionnaire (containing the ELP measure) and the Newest Vital Sign (NVS) as a measure of health literacy to Hispanic parents/caregivers. Data from the electronic medical record of the Hispanic parent/caregiver's child was reviewed for ED utilization within the past year.

This study's research design used health literacy as an independent variable, and emergency department (ED) utilization as the dependent variable; English language proficiency was included as a covariate to health literacy. The nature of the setting and this researcher's work role in the setting precluded construction of either a quasi-experimental or experimental design.

Threats to internal validity were present in this study. The study design was a cross-sectional study that took into consideration data from a single point in time. The study did not use random sampling and study findings could not be generalized. English language proficiency (ELP) was not measured with a validated tool and only perceived ELP was measured for both spoken ELP and reading ELP. Data was collected from one outpatient pediatric primary care office in a specific urban setting. Furthermore, data collection took place during the "busy"

season for the pediatric primary care office and could have potentially skewed the research findings. Figure 1 illustrates this study's proposed design.

Figure 1. Health Literacy, ED Utilization, and ELP



Research Question and Hypothesis

This study aimed to explore the following research question: “*Are there significant differences between levels of health literacy and emergency department utilization rates when controlling for level of English language proficiency in Hispanic parents/caregivers?*” The research question was guided by the following hypothesis: “*Hispanic parents/caregivers with higher levels of health literacy utilize emergency department services at lower rates when controlling for levels of English language proficiency.*”

Sampling Size and Methods

This study utilized a non-probability, convenience sample of 101 participants over a period of 3 months (August 2017-October 2017). A total of 112 Hispanic parents/caregivers were approached for this study of which 11 declined participation. The consent rate for this study was 90.18%. The inclusion criteria for eligible participants in this study included: (1) Hispanic

male and female parents/caregivers who speak Spanish and/or English, (2) were at least 18 years of age or older with legal guardianship over a child 10 years of age or younger, and (3) were presenting to the outpatient pediatric office for a routine or non-urgent medical appointment with their child who is 10 years of age or younger. Exclusion criteria included: (1) parents/caregivers under the age of 18, (2) parents/caregivers that were non-Hispanic, (3) foster parents (consent for medical treatment or consent for this study could not be provided by foster parents in Delaware), (4) Hispanic children with Division of Family Services (DFS) case managers since the case managers do not provide direct care to the child, (5) children who were new patients or who recently transferred primary care services (less than a year ago). In an effort to avoid erroneously perceived coercion, Hispanic parents/caregivers that were currently working with the principal investigator in her “care coordination” role at the primary care office were not eligible for this study.

The location for recruitment was one outpatient pediatric primary care office located in Wilmington, Delaware that primarily served a large, diverse Hispanic population. To determine eligibility for the study the principal investigator reviewed the daily appointment calendar for all medical providers and identified Hispanic parents/caregivers that were scheduled for an appointment at the office with their child who was 10 years of age or younger. Once the patient and parent/caregiver arrived to the office for the scheduled appointment, checked in at the front desk and were roomed, the principal investigator approached the eligible parents/caregivers regarding the study. The researcher explained the study and informed consent to the Hispanic parent/caregiver. Potential participants were offered time to review the informed consent and ask questions. Once informed consent was obtained, data was collected from the participant in a mutually agreed upon setting. At the completion of the demographic questionnaire and Newest

Vital Sign (NVS), the parent/caregiver was asked if he/she would like to participate in a random drawing for a chance to win one of four \$25.00 gift cards. If agreeable, the parent/caregiver's name was written on a piece of paper and entered in a locked box. Funding for the gift cards used in this study came from the principal investigator. The random drawing took place at the end of December 2017 and winners were contacted by phone by the principal investigator to pick-up the gift card at the pediatric office. Approval from the Institutional Review Board (IRB) of Nemours was received for this study. The IRB of Kutztown University of Pennsylvania agreed to defer review of this study to the Nemours IRB and agreed to accept the decision of the Nemours IRB. The written response of the Nemours IRB was forwarded to the Kutztown University of Pennsylvania IRB.

Study Site

The study site was located in an urban setting with free parking for families/patients. The office staff consisted of one full-time (4 days a week) nurse practitioner (NP) and four full-time pediatricians. Two of the pediatricians were recent hires/graduates from medical school and officially started seeing patients as of August 2017. The two new pediatricians worked extended hours, 7:30am to 6:45pm, on a rotating basis Monday to Friday. However, this office schedule was new and the office was working towards advertising the new office hours that were previously a standard 8:00am to 5:00pm. Four bilingual registered nurses (RNs) were on staff, four bilingual medical assistants (MAs), four bilingual patient service representatives (PSRs), one social worker, and one lead psychologist with four psychology residents (2 bilingual) were part of the support staff for the office. Weekend coverage, Saturday and Sunday, from 8:15am to 1:15pm, was available every weekend but the appointments were offered at a different location making it hard for some families to travel to the weekend location. Weekend coverage by the on-

call phone nurse and medical provider was not always provided by staff that spoke Spanish/English. Hispanic families would need to use an interpretation service to communicate with staff on the weekends if bilingual Spanish/English staff was not scheduled to work.

Human Subjects Protections

To obtain consent by participants, the researcher explained the study, confidentiality, planned use of data and that participation in the study was voluntary and participants were free to withdraw at any time. Individuals reviewed the information and informed consent form (Appendix A and B) in the language of their choice, English or Spanish, on site prior to completing the demographic questionnaire and Newest Vital Sign (NVS). A copy of the consent form was provided for their personal records. The study posed minimal risk to individuals participating.

All participants received a unique random identification number once data collection was completed. The researcher never used participant names, identifying information or information without written permission. If information from this study is published or presented at scientific meetings, names and other personal information will not be used. All printed records were stored in a locked filing cabinet at the pediatric office in compliance with Nemours IRB and the Health Insurance Portability and Accountability Act (HIPPA). The records of this study were kept confidential and are stored on a password-protected server accessed only by the primary researcher. However, the researcher cannot guarantee total privacy. Records can be opened by court order or produced in response to a subpoena or a request for production of documents.

Study Variables and Measures

A demographic questionnaire was developed in English and Spanish to collect data on the parent/caregiver: date of birth, relationship to the child, place of birth, number of years living in the United States, name of country where the parent/caregiver's parents were born, gender, marital status employment status, last year of school completed, and self-reported English language proficiency (Appendix C and D). The demographic questionnaire was pilot tested by the researcher with five bilingual (Spanish/English) adult staff members in the pediatric office to ensure proper translation and content validity. The Spanish version of the demographic questionnaire is a certified accurate translation.

Variables

Independent variable: Health Literacy

The Newest Vital Sign (NVS) was used to measure health literacy in all Hispanic parents/caregivers. The NVS is publically available through the Pfizer Clear Health Communication Initiative (2002) in English and Spanish as a validated tool to measure health literacy using a nutrition label with six questions (Appendix E and G). At the time of the study, parents/caregivers were provided with the nutrition label and the principal investigator asked six questions, in sequence, with answers recorded on a score sheet that accompanies the NVS (Appendix F and H). Each question on the NVS is worth one point and scores in the range of 0-1 were indicative of "high likelihood (50% or more) of limited literacy", 2-3 of "possibility of limited literacy", 4-6 of "adequate literacy". According to the research on average, the NVS takes about three minutes to complete (Weiss, Mays, Martz, Castro, DeWalt, Pignone, Mockbee, & Hale, 2005). The NVS was developed for use in primary care settings, and has good reliability (Cronbach α >0.76 in English and 0.69 in Spanish) (Weiss et al., 2005). Research on parental

health literacy has found that parents/caregivers of children were typically younger compared to the overall adult population and the NVS has demonstrated to work well in measuring health literacy of young (median age of 32) parents/caregivers (Morrison, Schapira, Hoffmann, & Brousseau, 2014; Weiss et al., 2005).

Health literacy is a categorical variable that reveals three different comparison groups: limited literacy, possibility of limited literacy, and adequate literacy. Health literacy was conceptualized as “the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions” (U.S. Department of Health and Human Services, 2011, p. ES-1). Health literacy was operationalized as a score from 0-6 with associated categories of limited literacy, possibility of limited literacy, and adequate literacy based on the results of the Newest Vital Sign (NVS). Scores on the NVS ranging from 0-1 were indicative of “high likelihood (50% or more) of limited literacy,” 2-3 of “possibility of limited literacy,” and 4-6 of “adequate literacy.”

Covariate: Self-Reported English Language Proficiency

Self-reported English language proficiency (ELP), a covariate, was a continuous, composite variable constructed from two questions on the demographic questionnaire that asked for the Hispanic parent/caregiver’s perceived spoken and reading ELP. ELP was conceptualized as how well the parent/caregiver perceives that they speak and read English. This was operationalized as a score from 1-6 on a Likert scale: 1 is “Strongly Disagree,” 2 is “Disagree,” 3 is “Mildly Disagree,” 4 is “Mildly Agree,” 5 is “Agree,” and 6 is “Strongly Agree.”

Dependent Variable: Emergency Department Utilization

Review of the child’s medical record, with parent/caregiver consent, was conducted retrospectively from the date the consent form was signed for emergency department (ED)

utilization within the past year (365 days). The number of ED visits for the child that did not result in a hospital admission were recorded.

Emergency department (ED) utilization is a continuous variable ranging from 0-365 and was conceptualized as a visit to the ED that did not result in an admission to the hospital as recorded in the child's electronic medical record during the past 365 days as of the date on the signed consent form. ED utilization was operationalized as the number of ED visits that did not result in an admission to the hospital. However, it is important to note the ICD-10 codes were not reviewed and it cannot be assumed that all ED visits that did not result in an admission were not emergent.

Data Analysis Plan

Data analysis was conducted using the Statistical Package for the Social Sciences (SPSS) available through Kutztown University of Pennsylvania and Millersville University of Pennsylvania.

For all variables in the study, descriptive data analysis was performed to show data percentages, frequencies, standard deviations, means, and histograms of the study sample demographic, independent, and dependent variables. These analyses and graphs also served to verify normality and linear relationships for the hypothesis-testing analysis.

Levene's Test for Equality of Variances was conducted to verify the assumptions of the analysis of variance (ANOVA) of homogeneity of variance. The hypothesis was analyzed using ANOVA to explore the main effects on the dependent variable by the independent variable, while entering English language proficiency (ELP) as a covariate effect on the dependent

variable. A Bonferroni *post hoc* test was used to control for Type 1 errors and individual group differences.

Chapter 4

Analysis

This chapter presents the configuration of the data, integrity to the assumptions of the statistical test procedures, and the results from the statistical tests of the hypothesis. Additional results aside from the main hypothesis will also be presented.

Configuring the Data

The raw data were originally entered into a Microsoft Excel spreadsheet during the process of data collection and comprised the following variables: the medical record number (MRN), gender of the pediatric patient, participant identification number (ID), language preference of the parent/caregiver for participation in the study, health literacy score, number of emergency department (ED) visits in the last 365 days as of the date on the consent form, the child's age, the parent/caregiver's age, relationship to the child, parent/caregiver's country of birth, the number of years the parent/caregiver has lived in the United States, what country the mother of the parent/caregiver was born, the country the father of the parent/caregiver was born, parent/caregiver's gender, parent/caregiver's marital status, parent/caregiver's employment status, parent/caregiver's last year of school completed, the parent/caregiver's self-reported ability to speak English well, and the parent/caregiver's self-reported ability to read English well. The MRN was only retained to cross-check data to ensure accuracy when entering data into the Microsoft Excel spreadsheet and not included in the data analysis. The Microsoft Excel spreadsheet was imported into the Statistical Package for the Social Sciences (SPSS) for the purpose of data analysis.

Data that was numeric remained the same, such as age and the self-reported English language proficiency on the Likert scale, but other data such as gender was coded into numbers for the purpose of data analysis in the Statistical Package for the Social Sciences (SPSS). The Newest Vital Sign (NVS) measured health literacy into three categories: high likelihood of limited literacy, possibility of limited literacy, and adequate literacy. The first category, high likelihood of limited literacy, was coded as 1; the second category, possibility of limited literacy, was coded as 2; and the third category, adequate literacy, was coded as 3.

The gender of the pediatric patient was coded as 1 for female and 2 for male. Language preference of the Hispanic parent/caregiver for participation in this study was coded as 1 for Spanish and 2 for English. Parent/caregiver's relationship to the child was coded, in order, from 1 to 9 (biological mother, biological father, maternal grandmother, maternal grandfather, parental grandmother, paternal grandfather, aunt, uncle, and other). Place of birth for the parent/caregiver was coded, in order, from 1 to 11 (Mexico, Columbia, Dominican Republic, USA, Puerto Rico, El Salvador, Guatemala, Honduras, Ecuador, Germany, and Paraguay). The same codes used for the parent/caregiver's place of birth were used to code the place of birth of the parent/caregiver's mother and father. Gender for the parents/caregivers was coded as male (1), female (2), and other (3). The parent/caregiver's marital status was coded as divorced (1), living with partner (2), long term partner (not married, not living together) as (3), married (4), domestic partnership/civil union (5), single (6), separated (7), and widowed (8). Employment status of the parents/caregivers was coded as no (1), yes-part time (2), and yes-full time (3). The parent/caregiver's last year of school completed was coded as follows: sixth grade or less (1), seventh grade (2), eighth grade (3), ninth grade (4), tenth grade (5), eleventh grade (6), high

school diploma (7), some college (8), bachelor's degree (9), graduate degree (10), associate's degree (11), and other (12).

Statistical Test Assumptions

Analysis of variance (ANOVA) has three statistical assumptions: observations are independent, normally distributed, and have homogeneity of variance. The first assumption, independent observations, was fulfilled by collecting data for this study individually with one parent/caregiver. There was no interaction between research participants, group discussions, or multiple parents/caregivers that were simultaneously participating in the research study in order to avoid influencing each other.

The second assumption, normal distribution, was fulfilled by collecting enough independent observations to follow the *Central Limit Theorem* that stipulates that “the sum of independent observations having any distribution whatsoever approaches a normal distribution as the number of observations increases” and “sums of 50 or more observations approximate to normality” (Pituch & Stevens, 2016, p. 224). Since this study collected data from 101 different research participants, this assumption was met.

The third assumption, homogeneity of variances, was fulfilled with Levene's test for Homogeneity of Variances. Levene's test was conducted with the Statistical Package for the Social Sciences (SPSS) and determined to not be significant meaning that group variation was not significantly different ($F(2, 97) = 1.91, p = .153$) thus fulfilling the third assumption of homogeneity of variances.

The covariate, English language proficiency (ELP), was used since it could potentially “disturb” the relationship between health literacy and emergency department (ED) utilization

based off the identified gap in the literature review associated with health literacy and ED utilization among Hispanic parents/caregivers. The use of a covariate as a variable that could confound the main relationship in this study has been supported by Wildt and Ahtola (1978).

Results

Data collection took place between August 2017 and October 2017. A total of 101 research participants were enrolled in this study. Descriptive statistics on the research participants are shown in Table 2.

Table 2.

Hispanic parent/caregiver and child characteristics
(N=101)

Characteristic	Category	Percent	n
Parent's Gender	Female	90.0%	91
	Male	10.0%	10
Child's Gender	Female	37.6%	38
	Male	62.4%	63
Parent/Caregiver's Country of birth	Mexico	58.4%	59
	Colombia	2.0%	2
	Dominican Rep.	1.0%	1
	United States	21.7%	22
	Puerto Rico	6.9%	7
	El Salvador	3.0%	3
	Guatemala	2.0%	2
	Honduras	2.0%	2
	Ecuador	1.0%	1
	Germany	1.0%	1
Paraguay	1.0%	1	
Parent/Caregiver's Family of Origin	Mexico (Mother and Father)	65.3%	66
	Colombia -Father	2.9%	3
	-Mother	2.0%	
	Dominican Rep. (Mother and Father)	2.0%	2

	USA		
	-Father	0.6%	4
	-Mother	2.9%	
	Puerto Rico		
	-Father	9.4%	17
	-Mother	7.9%	
	El Salvador (Mother and Father)	3.0%	3
	Guatemala (Mother and Father)	2.0%	2
	Honduras (Mother and Father)	2.0%	2
	Ecuador (Mother and Father)	1.0%	1
	Paraguay (Mother and Father)	1.0%	1
Employment Status	No	39.6%	40
	Part-time	21.8%	22
	Full-time	38.6%	39
Education			
	6 th grade or less	8.9%	9
	7 th grade	1.0%	1
	8 th grade	2.0%	2
	9 th grade	27.7%	28
	10 th grade	5.9%	6
	11 th grade	8.9%	9
	H.S. diploma	22.7%	23
	Some college	8.9%	9
	Bachelor's Degree	4.0%	4
	Graduate Degree	2.0%	2
	Associate's Degree	4.0%	4
	Other (Certificate)	4.0%	4
		Mean	
		(Years)	
Parent's Age		31.8	
Child's Age		4.06	
Years living in United States		17.5	

Among the 101 research participants, 38.6% (n=39) tested as having a high likelihood of limited literacy, 34.6% (n=35) tested as having a possibility of limited literacy, and 25.7% (n=26) tested as having adequate literacy based off the Newest Vital Sign (NVS) instrument. The study identified 2 patients who used the emergency department (ED) services 4 time in one year and can be considered “super-utilizers” based on the Centers for Medicare and Medicaid Services (CMS). Although legal guardians could participate in the research study, all research participants were either the biological mother or father of the child. An overwhelming number of parents/caregivers, 64.4% (n=65), identified Spanish as their language of preference for research participation. The mean age of the Hispanic parent was 31.8 years old and 4.06 years old for the child. A majority of the Hispanic participants, 58.4% (n=59), reported Mexico as their place of birth. Twenty-eight percent (n=28) of the parents reported completing up to 9th grade in school and 23% (n=23) reported obtaining a high school diploma. Table 1 provides a deeper breakdown of the reported educational attainment of the Hispanic parents/caregivers. Some college education was obtained, 8.9% (n=9), but only 4.0% (n=4) of Hispanic parents/caregivers reported having a bachelor’s degree. Even less reported obtaining a graduate degree, 2.0% (n=2).

Statistical Tests of the Hypothesis

Tables three and four below show the results of the main effects of health literacy on emergency department (ED) utilization. The study found a significant effect of health literacy level on ED usage, $F(3, 97) = 16.97, p = .00$. However, a post-hoc test, Bonferroni, was conducted to control the Type 1 error rate and found no significant difference between any pairing of the groups. In light of the Bonferroni correction finding, the hypothesis of an effect of health literacy level on ED usage is not supported.

Table 3.
ANOVA: Number of ED Visits

Source	Sum of Squares	Df	Mean Squares	F	Sig.
Health Literacy Score	55.071*	3	18.357	16.970	.000
Error	104.929	97	1.082		
Total	160.000	100			

*R Squared=.344
(Adjusted R Squared=.324)

Table 4.
Pairwise Comparisons (Bonferroni) on number of ED Visits by Health Literacy levels

(I) Health Literacy	(J) Health Literacy	Mean	Mean Difference (I-J)	Std. Error	Sig. ^a
High likelihood of limited literacy	Possibility of limited literacy	.74	.082	.253	1.000
	Adequate literacy	.65	.196	.294	1.000
Possibility of limited literacy	High likelihood of limited literacy	.79	-.082	.253	1.000
	Adequate literacy	.65	.114	.277	1.000
Adequate literacy	High likelihood of limited literacy	.79	-.196	.294	1.000
	Possibility of limited literacy	.74	-.114	.277	1.000

^a. Based on estimated marginal means

Table 5 shows the results of the main effects of health literacy on ED utilization while controlling for perceived English language proficiency (ELP). The analysis found no significant effect on ED utilization when ELP was accounted for $F(3, 97) = 2.62, p = .055$. Hence, the hypothesis is not supported.

Table 5.
ANOVA with number of ED Visits and ELP

Source	Sum of Squares	Df	Mean Squares	F	Sig.
ELP	.196	1	.196	.180	.673
Health Literacy Score	8.564*	3	2.855	2.617	.055
Error	104.733	96	1.091		
Total	160.000	100			

*R Squared = .345 (Adjusted R Squared = .318)

Other Analyses: Correlation Matrix and Simple Regression

A correlation matrix is displayed in Table 6. A significant relationship between health literacy score and the number of years living in the United States was found, $r(98) = .22, p = .025$. The health literacy score of Hispanic parents/caregivers was significantly correlated with the last year of school completed, $r(98) = .46, p = .000$, employment status $r(98) = .22, p = .025$, the perceived spoken English language proficiency (ELP) $r(98) = .38, p = .000$, and the perceived reading ELP $r(98) = .48, p = .000$.

Table 6.
Correlations with Health Literacy

Hispanic Parent/Caregiver	Parent Demographics				
	Years living in the U.S.	Last year of school completed	Employment status	English Speak	English Read
Health Literacy	.224*	.458**	.224*	.384**	.480**

* $p < .05$ ** $p < .01$

A simple linear regression was calculated, see Table 7, to predict the health literacy score based on the number of years a Hispanic parent/caregiver has living in the United States. A significant regression equation was found ($F(1,98) = 5.161, p < .025$), with an R^2 of .050. Participant's predicted health literacy score is equal to $1.497 + .021(\text{number of years living in the}$

United States) when the number of years a Hispanic parent/caregiver has living in the United States is measured in years. Participant’s health literacy score increased .021 for each year the Hispanic parent/caregiver reported living in the United States.

Table 7. Linear Regression: Health Literacy and Number of Years Living in the United States

	Coefficients				
	Unstandardized Coefficients		Standardized Coefficients		
	B	Std. Error	Beta	t	Sig.
Constant ^a	1.497	.182		8.229	.000
Years living in the United States	.021	.009	.224	2.272	.025

a. Dependent Variable: Health Literacy Score

A second simple linear regression was calculated, see Table 8, to predict how well a Hispanic parent/caregiver will speak English based on the number of years living in the United States. A significant regression equation was found ($F(1,99)=38.684, p<.000$), with an R^2 of .281. Participant’s predicted English speaking abilities is equal to $2.074 + .109$ (number of years living in the United States) when the number of years a Hispanic parent/caregiver has living in the United States is measured in years. Participant’s English speaking abilities increased .109 for each year the Hispanic parent/caregiver reported living in the United States.

Table 8. Linear Regression: Speaking English and Number of Years living in the United States

	Coefficients				
	Unstandardized Coefficients		Standardized Coefficients		
	B	Std. Error	Beta	t	Sig.
Constant ^a	2.074	.339		6.116	.000
Years living in the United States	.109	.017	.530	6.220	.000

a. Dependent Variable: Speaking English

The same simple linear regression was calculated, see Table 9, to predict how well a Hispanic parent/caregiver will read English based on the number of years living in the United States. A significant regression equation was found ($F(1,99)=33.819, p<.000$), with an R^2 of .255. Participant's predicted English reading abilities is equal to $1.863 + .112$ (number of years living in the United States) when the number of years a Hispanic parent/caregiver has living in the United States is measured in years. Participant's English reading abilities increased .112 for each year the Hispanic parent/caregiver reported living in the United States.

Table 9. Linear Regression: Reading English and Number of Years living in the United States

	Coefficients				
	Unstandardized Coefficients		Standardized Coefficients		
	B	Std. Error	Beta	t	Sig.
Constant ^a	1.863	.375		4.971	.000
Years living in the United States	.112	.019	.505	5.815	.000

a. Dependent Variable: Reading English

Chapter 5

Discussion and Conclusion

This chapter provides an in-depth discussion of the research findings presented in Chapter 4 and the additional findings in relationship to the theoretical framework, *Human Capital Theory*. Strengths and limitations of the study are discussed with implications and recommendations for social work leadership and research.

Findings

This study did not find, as hypothesized, that Hispanic parents/caregivers with higher levels of health literacy utilize the emergency department (ED) at lower rates. This finding may be due to the lack of variance in the dependent variable (ED utilization) that only ranged from 0-4, the clinic setting where most patients already have an established primary care provider, and the limited sensitivity of the Newest Vital Sign (NVS) to measure health literacy into three categories. The second hypothesis, that English language proficiency acted as a mediating variable between health literacy and ED utilization is not addressed, since it is moot in light of the rejection of the first hypothesis.

The health literacy research landscape is vast and expanding as health care services advance with technology and patient care evolves with higher demands on self-management skills for patients. Wallace (2010) detailed health literacy as a multifaceted skill composed primarily of four interconnected areas: numeracy skills, reading and writing skills, cultural and conceptual knowledge, and speaking and listening skills. Research in health literacy has documented the connections between low health literacy and health outcomes. Yet, gaps remain in the health literacy research field for multiple vulnerable populations and for a vast array of medical conditions in multiple age groups navigating through different medical services. The complicated

and vast health care system has an equally complex and vast health literacy variable that requires on-going research. In this particular study, the health literacy of Hispanic parents/caregivers was not found to reduce emergency department (ED) utilization. However, findings from this study cannot be generalized and future health literacy research should take into consideration the identified limitations of this study, improve upon them, and continue to explore the role of English language proficiency (ELP) within the context of health literacy and ED utilization for Hispanic parents/caregivers. Failing to find statistically significant results in this study does not equate failure. Rather, this study can inspire future social work research in health literacy for many vulnerable populations.

A strong push is underway for many health care providers to reduce costs and improve health outcomes for all populations. In light of the Affordable Care Act (ACA), private insurance companies and Medicare/Medicaid programs that contract with health care providers are increasingly abandoning the “fee for service” contracts and embracing value-based care that holds health care providers responsible for meeting certain health benchmarks, like a specific immunization rate, and basing compensation on meeting those benchmarks while cutting costs and managing chronic health conditions for overall better health outcomes (Burwell, 2015). This approach represents greater opportunities for large scale improvements in population health and carries higher risk for health care companies that need to actively manage the use of health care resources of its patients, develop interventions for vulnerable populations/high-risk groups, and maintain their bottom line while transitioning to a new reimbursement platform. Basing compensation on the responsible use of health care resources and placing responsibility on health care providers for health outcomes shifts risk to health care providers and changes how health care will address social determinants of health (Bailey, 2017).

Future health literacy research that focuses on health outcomes and costs like ED utilization, asthma, and medication errors would benefit from recruiting large sample sizes outside of traditional health care settings like primary care offices, hospitals, walk-in clinics, specialty care offices, and urgent care centers to community resource/recreation centers and early childhood centers like Head Start. Research outside of fast paced and regimented settings would potentially allow for greater data collection that is not hindered by limited time and space from the health care facilities. Recruitment of health literacy research participants would further benefit from random sampling to include diverse Hispanic ethnic groups for research findings that can be generalized. Culturally sensitive testing instruments to measure health literacy would need to be translated into various Spanish dialects to capture the variations in the Spanish language and address the cultural and conceptual health knowledge that builds health literacy. Currently, a majority of health literacy research conducted is quantitative in nature. Yet, health literacy is a multi-level skill set and qualitative work, unlike many validated tools to measure health literacy like the Newest Vital Sign (NVS), can potentially be more sensitive in collecting data related to cultural and conceptual knowledge related to health literacy. Re-focusing health literacy research on qualitative research can provide a different outlook on low health literacy from a parent/caregiver's perspective to further inform future health literacy research, interventions, and policy development.

Strengths and Limitations of the Study

One strength of this study was the pediatric primary care setting since it already provided pediatric patients and their Hispanic parents/caregivers with medical staff (nurses, medical assistants, front staff, and providers) that fluently spoke Spanish and written information in Spanish. This helped capture a real level of health literacy without the “excuse” of a language barrier and poor service from interpretation services that are commonly cited as examples for

poor patient communication and understanding/compliance with treatment plans/health recommendations. Yet, having fluent speaking Spanish staff could have created a weakness in this study since the sample could be tainted with people who would be more likely to visit the primary care office rather than the emergency department (ED) even with Hispanic parents/caregivers that have low health literacy and thus confounding the results of this study. Furthermore, the health literacy of the Hispanic parent/caregiver was measured with a validated tool, the Newest Vital Sign (NVS), which was available in Spanish, proven to work well in younger populations, and developed for use in fast-paced primary care settings. Lastly, the principal investigator spoke fluent Spanish and data collection was completed without the use of an interpretation service.

Future studies can replicate and improve upon the research design and sampling method utilized in this study. One area for improvement, the sampling method, can be vastly improved upon by using random sampling to provide research findings that can be generalized. This study used a small sample size that can be improved upon by recruiting a larger sample size from community health centers/wellness centers, and non-medical facilities like Head Start programs with higher rates of Hispanic/Latino diversity. The research design used, a cross-sectional study and secondary data analysis, was another limitation for this study. The dependent variable (DV) data, emergency department (ED) utilization, was collected as secondary data from each pediatric patient's electronic medical record and the independent variable (IV) data, health literacy score, was collected at a specific point in time after the ED utilization took place. Controlling for how long a patient had been coming to the pediatric primary care office could have helped with the research design. The use of an experimental or quasi-experimental design would have diminished the threat to internal validity present in this study. A significant

improvement for future research could include measuring the health literacy and English language proficiency (ELP) of Hispanic parents/caregivers at the time the family joins the pediatric outpatient practice and follow these families for a year to measure the ED utilization for a year. Conducting research in a different setting like the emergency department would allow the researcher to focus on pediatric patients who do not have a primary care provider (PCP) or do a two-group comparison with those patients that do report having a PCP. After establishing a baseline health literacy score and ELP, the same families can have their health literacy and ELP re-measured a year later for any improvements and compare ED utilization over the year. Including ED utilization as one of several dependent variables of interest (e.g., medication adherence for asthma, diabetes, other chronic conditions; accident prevention; school attendance/truancy) may also be useful in helping to further understand how to tailor health literacy interventions to achieve maximum outcomes in this population.

Although the Newest Vital Sign (NVS) is a validated tool available in Spanish to measure health literacy, the NVS was not sensitive to all areas that influence the health literacy of an individual: numeracy, reading and writing, cultural and conceptual knowledge, and speaking and listening skills (Wallace, 2010). The NVS primarily focused on numeracy, reading, speaking, and listening skills with the format of the NVS tool, an ice cream nutrition label, and the instructions on how to administer the NVS (Pfizer Clear Health Communication Initiative, 2002). The NVS was validated to fall into three categories broken down by score: score of 0-1 suggests high likelihood of limited literacy, 2-3 indicates the possibility of limited literacy, and score of 4-6 indicates adequate literacy (Pfizer Clear Health Communication Initiative, 2002). Although each category had a “raw” score, it could not be used in the analysis since the tool was

not validated in that way. Identifying and utilizing a more sensitive and validated tool to measure health literacy could improve the data collection process and provide stronger findings.

Another limitation to this study relates to the dependent variable (DV) lacking variability. The data collected did not have a big spread in the number of emergency department (ED) visits. This lack of variability in the DV contributed to the drop in significance as shown in the post-hoc test. A more likely explanation is that the majority of the parents/caregivers in this study did not utilize the ED inappropriately, since the range was only 0-4 ED visits over the past year. In this case, data collection took place in one urban outpatient pediatric primary care office during the “busy” season and could have potentially skewed the data. Extending the data collection period outside of the “busy” season could potentially capture greater variability and diminish the possibility of skewing the data.

The setting further contributed to limitations in this study not only because data came from one office, but the setting had time limitations where patients could only be approached before or after a scheduled pediatric appointment. Recruitment became especially difficult if the Hispanic parent/caregiver had a sick child or multiple children with him/her that demanded attention. Hence, the number of Hispanic parents/caregivers that could participate in this study could be skewed towards smaller families, families with fewer children presenting to the office, and fewer families with sick children given the research design for this study. Attempting to engage a patient after the visit was completed and the child was administered a vaccine was a challenge and disruptive to the research process as the parent could not attend to the information requested and console a crying child. Given the time constraints presented by the setting where data collection took place, English language proficiency (ELP) was not measured with a validated tool given that most ELP tools require a significant amount of time to administer and

score. Instead, ELP was measured with a Likert scale where Hispanic parents/caregivers self-rated their ability to speak and read English. This presented the possibility of Hispanic parents/caregiver over rating or under rating their ELP abilities. The Hispanic parent/caregiver's abilities to write in English were not directly assessed using the Likert scale on the demographic questionnaire. Research participants were only Hispanic parents/caregivers and excluded all other ethnic groups.

Although purposefully designed to capture emergency department (ED) usage data from the electronic medical record (EMR) of pediatric patients, the sample was limited to Hispanic caregivers with children ten years of age or younger. This purposeful limit was adopted given the recent implementation of the EMR within the research setting/outpatient pediatric primary care office (within the last 12 years). Furthermore, data on ED utilization was obtained from the child's EMR within one large health care system. ED utilization within other health care systems was not assessed leading to the possibility of missed ED utilization data from other local and regional hospitals. Including older children could have provided a wider view of ED utilization, health literacy, and perceived English language proficiency (ELP). Future studies may want to examine the diagnosis codes for ED visits to determine whether the visit was actually for an emergent reason versus a non-emergent reason.

Findings in Relation to Theory and Literature

The theoretical foundation for this study, *Human Capital Theory*, suggests that humans invest in themselves to create "capital" in many non-conventional forms such as knowledge/education and health that are used to enhance an individual's productivity and skill level. This translates into greater "human capital" for obtaining better paying jobs and maintaining optimal health. Human capital does not refer to stocks, bonds, or other physical

resources that humans can have, although this does aid with obtaining further human capital. Both education and health foster an increasingly more productive individual compared to those with less education and poor health. Human behavior can build human capital by engaging in various short-term and long-term goals. Short-term goals to build human capital include shelter, food, and meeting basic necessities that support the pursuit of long-term goals like completing a degree that further increases the individual's human capital.

This study purposefully looked at health literacy level and English language proficiency (ELP), both the ability to speak and read in English, of Hispanic parents/caregivers as “human capital.” The health literacy of the Hispanic parent/caregiver is a form of knowledge and a skill needed to effectively and efficiently navigate the health care system for the optimal growth and development of the pediatric patient. This includes understanding and following medical advice for preventative care and sick/acute care and knowing what level of care to access based on the presenting health concern. Historically, the utilization of health care services/resources has provided multiple research opportunities and findings that have highlighted the connections between health literacy and emergency department (ED) utilization.

The level of health literacy held by parents/caregivers provides human capital for the beneficial and efficient use of health care services and resources. Health literacy is a critical skill for the parent/caregiver of a pediatric patient who primarily relies on the parent/caregiver for health care decision making that includes understanding what constitutes a fever, how to adequately dose medication, how to manage chronic health conditions (asthma, diabetes, etc.), and how to navigate the health care system. Hispanic parents/caregiver that lack the necessary health literacy skills to manage the health care needs of pediatric patients ultimately affect the health of the child.

The correlation matrix presented in this study (Table 5) further supports the theoretical approach, *Human Capital Theory*, taken by this study. The health literacy level correlated with the number of years living in the United States $r(98)=.22$, $p=.025$, the employment status $r(98)=.22$, $p=.025$, the last year of school completed $r(98)=.46$, $p=.000$, and both the spoken English language proficiency (ELP) of the Hispanic parent/caregiver $r(98)=.38$, $p=.000$, and the reading ELP $r(98)=.48$, $p=.000$. Likewise, the three simple linear regressions presented in Chapter 4 further showed how health literacy increased with the number of years a Hispanic parent/caregiver reported living in the United States along with an increase in both reading and speaking capabilities in English as parents/caregivers live longer in the United States. These variables were measured in part to provide descriptive statistics and as variables that can increase the human capital of an individual because they either aid or contribute to the skill level of the individual. The study found a strong correlation between health literacy and the number of years the Hispanic parent/caregiver had been living in the United States. Potentially, the more years a Hispanic parent/caregiver has living in the United States, the more the parent was acculturated and familiarized with the American health care system. The acculturation and familiarization would aid in developing the knowledge and skills needed to navigate the health care system to obtain better health care outcomes and access the appropriate level of care since parents would be more likely to have a primary care doctor and have a chosen pharmacy to dispense medications. However, in this study the human capital built by Hispanic parent/caregivers over years of living in the United States did not translate into lower ED utilization rates as hypothesized. Potential explanations for this could be that the human capital that was built (employability, speaking and reading in English skills) was not sufficient to deter ED utilization

and cultural differences in the perception of ED services and using/accessing ED services was not taken into consideration or measured in this study.

Employment status speaks directly to human capital. A majority of the Hispanic parents/caregivers that participated in the study were females (90%, n=91) and reported no employment (39.6%, n=40). Of the 40 females who reported no employment, 47.5% (n=19) scored as having a “high likelihood of limited literacy” and 32.5% (n=13) scored as having a “possibility of limited literacy” based off the Newest Vital Sign (NVS) scoring criteria for measuring health literacy. Only 20% (n=8) of female Hispanic parents/caregivers that reported no employment scored as having adequate health literacy. Of the females that reported full-time employment (n=30), 46.7% scored as having adequate health literacy compared to 10% (n=20) of the females that reported part-time employment. Overall, these findings support the concept of health literacy as a skill that builds human capital since a majority of the full-time and part-time employed females scored significantly higher on the NVS compared to females that reported no employment. These findings support the use of employment status as a question in the screening criteria for the identification of individual with higher risk for low health literacy. Screening for health literacy in health care settings would not only benefit from short and simple screening tools but also discrete questions like employment status that reduce the level of shame potentially experienced by patients who engage in health literacy screenings. Shame is a powerful emotion that has the potential to discourage participation in health literacy screenings, and can disrupt the patient/provider communication needed for health care treatment planning and good health outcomes. Parents/caregivers, especially those with low health literacy, need to ask questions and seek clarification without fear or shame. Medical providers need to identify those with

potentially low health literacy and modify how health information is delivered to maximize understanding, promote discussion/questions, and minimize shame.

The last year of school completed is an essential variable linked to human capital given the strong link between education and the income/productivity potential of an individual through their viable work years (Becker, 1993; Hartog & Maassen van den Brink, 2007; Schultz, 1961). This study found that 27.7% (n=28) of Hispanic parents/caregivers reported completing up to 9th grade. It is important to note that a majority of these respondents identified Mexico as their country of birth (n=24). One explanation for the lack of academic gain in this population is that the federal government for Mexico only recently provided public education until 12th grade/high school and this option was not available when many of the Hispanic parents/caregivers were of school age (Secretaria de Educacion Publica, 2017). During the middle school and high school years of many of the Hispanic parents/caregiver, further education beyond middle school (completing a high school degree), would require a student in rural Mexico to commute and gain “entrance” into a high school. Only 22.7% (n=23) reported completing a high school degree and those Hispanic parents/caregivers primarily reported Mexico (n=13), United States (n=5), Puerto Rico (4), and Paraguay (n=1) as the country of birth. The Hispanic parents/caregivers that reported having a Bachelor’s degree (n=4) primarily came from Puerto Rico (n=2), Colombia (n=1) and Mexico (n=1). These findings again speak to the lack of investment in accessible education opportunities in many Hispanic/Latin American countries that then see immigrating to the United States as an option not only for employment opportunities but increased access to education opportunities for their children.

Implications and Recommendation for Social Work Leadership and Future Research

Social work leadership is needed for collaboration with the medical field in multidisciplinary teams to fortify the foundation of health care reform in the United States with research that guides informed policy development. Currently, many initiatives are in place like the patient-centered medical home and value-based care payment models to promote increased health outcomes, coordinate medical care, and reduce health care costs. Social determinants of health that are commonly discussed include poverty, living in high crime rate areas, and “food deserts,” but lack emphasis on health literacy. Social work leadership can begin by highlighting the effect of health literacy on vulnerable populations through advocacy work and building awareness among the social work profession and educational institutions that instruct and prepare future generations of social work leaders and researchers. Awareness is how interest in health literacy can be inspired for interdisciplinary collaboration in health literacy research and policy development.

Future research in Hispanic parent/caregiver health literacy is warranted to better understand the role of English language proficiency (ELP) in relation to emergency department (ED) utilization. This is especially critical as health care providers seek to improve health outcomes and reduce health care costs. Given the concern for time constraints and to minimize any shame associated with low health literacy, future research in health literacy should look at data collection outside of the pediatric primary care office to facilitate a more flexible environment to administer both validated tools to measure health literacy and ELP.

Lastly, more qualitative research is needed specific to health literacy and Hispanic parents/caregivers to capture the parent’s perspectives. Current health literacy research is overwhelmingly quantitative in nature. The use of focus groups and individual interviews in the

community and health care centers can potentially shed light on varying health literacy perceptions from parents/caregivers and direct health literacy research in different directions that could have potentially been overlooked with the overwhelmingly quantitative focus on health literacy research. Potential research questions that qualitative research should explore are: “How do Hispanic parents/caregivers define health literacy?”, “Is health literacy perceived by Hispanic parents/caregiver to be of importance and effect health outcomes?”, “How do medical providers cause parents/caregivers to be reluctant to ask questions?”, “Can providers encourage more questions from parents/caregivers that can improve health literacy?”, “What would parents/caregivers advise providers to do to be most helpful in providing care to their children?”, and “What role does the patient-centered medical home have in promoting or hindering health literacy for Hispanic parents/caregivers?”

Conclusion

Gaps within health literacy research are prominent, especially within the Hispanic parents/caregiver population directly related to pediatric patient’s use of the ED. The social work profession has an opportunity and obligation to address the gaps in the literature as a means of driving the development of evidence based interventions/programs for this vulnerable population. Furthermore, advocacy is needed to bring research findings to the political conversation surrounding health care reform to guide the future health care policies at the state and federal level. As social workers continue to work in multidisciplinary teams within all levels of the health care system, contributing and collaborating with other professionals to address health literacy is a viable way to elevate the social work profession as an essential partner in the research and development of programs and policies for better health outcomes in the pediatric population. Undoubtedly, the enactment of the Affordable Care Act (ACA) and the shift to

value-based care further fuels the momentum to address social determinants of health to increase health outcomes while reducing health care costs. The health literacy of patients will play a pivotal role in the self-management capabilities of individuals, as well as the success of value-based care aimed to transform health care services and outcomes in the United States. Failing to take into consideration health literacy as a critical variable in meeting health care outcomes and policy development will slow the national-wide efforts of many health care providers and stakeholders working to increase efficiency and improve health care outcomes for vulnerable populations/patients of the health care system in the United States.

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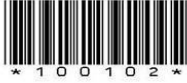
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Appendix A

Nemours Consent Form



Nemours
Parental Permission and Informed Consent for
Participation in a Research Study

Nemours IC / PP Template May 2017

You have been asked to be in a research study with your child. This form explains the research, your rights and your child's rights as research participants, and any responsibilities that you may have as a result of you and your child's participation. You should understand the research study before you agree to be in it and to permit your child to be in it. ***You will receive a copy of this form. Read this form carefully. You may also talk with your family or friends about it. A research team member will answer any questions you have before you make a decision.***

1. WHAT IS THE TITLE OF THE STUDY? Hispanic parent/caregiver health literacy and English language proficiency: Variables affecting pediatric emergency department utilization.

2. WHO IS IN CHARGE OF THE STUDY AT NEMOURS?

If you have a question, complaint, or problem related to the study, you can call the investigator anytime at the numbers listed below.

Nemours - WIL	
Principal Investigator	Sandy A. Ramirez Sanchez, MSW
Co-Investigator(s)	Cheyenne Hughes-Reid, PhD Advisor
Study Coordinator(s)	
Address	701 North Clayton Street, Suite 400

	Wilmington, DE 19805
Daytime Phone	302-421-9706
After Hours Phone	610-633-6294
Long Distance	1-800-SOS-KIDS or 1-800-767-5437

3. WHO SHOULD RESEARCH PARTICIPANTS CONTACT ABOUT THEIR RIGHTS?

If you have questions about your rights as a research participant, what to do if you are injured, if you would like to offer input or obtain information, or if you cannot reach the investigator or want to talk to someone else who is not involved with this research, you may contact the persons listed below.

Chairperson, Nemours IRB 1 at 302-651-5970
 Director, Nemours Office of Human Subjects Protection at 302-298-7613
 Email address: NOHSP@nemours.org

4. WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to explore Hispanic parent/caregiver health literacy and emergency department (ED) utilization for children ages birth to 10 years of age from a single outpatient pediatric primary care office in Wilmington, Delaware. English language proficiency (ELP) will also be measured to determine whether ELP is a moderating variable for ED utilization in children of Hispanic parents/caregivers.

5. WHO IS SPONSORING OR PAYING FOR THE STUDY?

Sandy A. Ramirez Sanchez is the Sponsor of this study. No one will pay Nemours for its costs in conducting this study. This study is part of the dissertation requirement for Sandy A. Ramirez Sanchez to obtain her Doctor of Social Work (DSW) degree.

6. WHO CAN BE IN THE STUDY?

A Hispanic parent/caregiver at least 18 years of age or older, Spanish or English speaking, with legal guardianship of the child, 10 years of age or younger, seen at Nemours duPont Pediatrics, St. Francis for primary care services and is not scheduled as a new patient or for an urgent medical appointment.

7. HOW MANY OTHER PEOPLE CAN BE IN THE STUDY?

The study aims to enroll 360 participants from Nemours duPont Pediatrics, St. Francis.

8. HOW LONG WILL PARTICIPATION IN THE STUDY LAST?

Completing a demographic questionnaire and measuring health literacy using the Newest Vital Sign (NVS) will take about 15-20 minutes. The principal investigator will review the child's electronic medical record (EMR) at a separate time. Review of the EMR is expected to take about 15-30 minutes. No follow-up is needed.

9. WHAT ARE THE RESEARCH PROCEDURES?

- A) A parent/caregiver will have to sign this consent form and complete the following:
- B) The parent/caregiver will be asked to fill out a demographic questionnaire containing 11 questions that asks the parent/caregiver's date of birth, relationship to the child, parent/caregiver's place of birth, number of years parent/caregiver has lived in the United States, place of birth of the mother and father of the parent/caregiver, gender, marital status, employment status, last year of school completed, how well you speak English, and how well you read English.
- C) The parent/caregiver will then be asked to complete the Newest Vital Sign (NVS) to measure health literacy. The NVS is a validated tool that measures health literacy using an ice cream nutrition label and consists of 6 questions that take about 3 minutes to administer by the principal investigator.
- D) The principal investigator will review the child's Electronic Medical Record (EMR), with informed consent from the parent/caregiver, for Emergency Department (ED) visits within the last 365 days as of the date on this informed consent. The number of ED visits that did not result in a hospital admission will be counted.
- E) Parents/caregivers will be recruited for this study by convenience sample at Nemours duPont Pediatrics, St. Francis. The principal investigator will review the schedule for the day and approach eligible research participants when they arrive for their scheduled appointment regarding this study. All data collected will be completed in a private room within the Nemours duPont Pediatrics, St. Francis office before or after the child was seen for their medical appointment.
- F) **10. WHAT ARE POSSIBLE RISKS OF BEING IN THIS STUDY?**

Any research has some risks (things that could make you or your child sick, feel uncomfortable, or hurt). The risks with the most chance of happening to someone in this study are listed below. Also, there is a chance of other risks that almost never happen, or unknown risks.

Some parents/caregivers might feel embarrassed or ashamed of disclosing their English language proficiency or having their health literacy tested, especially if the parent/caregiver has low health literacy. In an effort to minimize feelings of embarrassment or shame, all information collected will be done in private. If parents/caregivers feel they need additional support, they will be provided with information on bilingual behavioral health services in the community.

Risk of participant disclosure/loss of privacy is possible, but precautions will be taken to ensure this does not occur.

11. WHAT ARE THE POSSIBLE BENEFITS OF BEING IN THIS STUDY?

There are no direct benefits of participating in this study. However, the findings can potentially help identify if health literacy is an issue that the medical staff at Nemours duPont Pediatrics, St. Francis need to take into consideration when communicating with patients and families verbally and in writing.

12. WHAT HAPPENS IF A PROBLEM OR INJURY RESULTS FROM THE RESEARCH PROCEDURES?

Nemours will assure that you / your child receives treatment, if needed, for study-related injuries. Neither Nemours nor the study principal investigator has a program to pay for medical care provided to treat the injury. If you and / or your child have health insurance, it may, or may not pay for the cost of treatment resulting from a study-related injury. If insurance does not pay, or if you or your child do not have insurance, you understand that you may be responsible for paying for the cost of treatment.

If you think that you or your child has been injured while in this study or has a problem related to the study, you should tell the principal investigator as soon as possible. The principal investigator or research staff will tell you what you should do. The principal investigator and phone numbers are on the first page of this form.

The study staff is available Monday - Friday from 8:00am to 5:00pm. During these hours, you should call _Nemours duPont Pediatrics, St. Francis 302-421-9700___ for medical advice.

During evenings, weekends, and holidays, you should call _302-421-9700__. You will reach the Nemours Kids Health on-call.

13. IS BEING IN THE STUDY VOLUNTARY?

Being in this study is totally voluntary. Anyone who takes part in the study can stop being in it at any time. There will be no change to your or your child's usual medical care if you or your child decide not to be in the study or decide to stop being in the study. No one will be angry with you or your child, or treat you or your child any differently than before you or your child were asked to be in the study. However, this study requires the participation of both you and your child; if you decide to stop being in the study, your child's participation will also end.

If you stop participation in this study, you and your child may continue treatment with your and / or your child's doctors, or you may seek treatment from another doctor of your choice.

In the event that you and your child withdraw from the study, the study doctor may ask your permission to continue study follow-up, and all clinical data related to the study may continue to be collected from your child's medical records.

You may ask the researcher to destroy your and / or your child's information or samples. Your request must be in writing. The researcher will tell you if this is possible. There may be legal reasons for keeping your and / or your child's information or samples.

If you decide to drop out of this study, there are no foreseeable adverse consequences.

14. WHAT OPTIONS ARE AVAILABLE OTHER THAN BEING IN THIS STUDY?

You and your child can refuse participation in this study. There may be other research choices that could be considered. These choices include:

Health literacy research conducted at Nemours in the future or by other health care systems or organizations. The principal investigator is not currently aware of any other health literacy research in the area.

15. CAN THE RESEARCHERS REMOVE SOMEONE FROM THE STUDY?

If participants do not meet the requirements for this study like age of parent/caregiver (18 years of age or older), nationality, have a child 10 years of age or younger, and do not have legal guardianship they will not be permitted to participate in this study.

16. WHAT ARE THE COSTS OF BEING IN THIS STUDY?

There are no financial costs to the parents/caregivers who participate in this study. Indirect costs include time before or after the child's scheduled medical appointment to complete this study.

17. WILL WE BE PAID FOR BEING IN THIS STUDY?

After providing informed consent, completing the demographic questionnaire and the Newest Vital Sign (NVS), the parent/caregiver will be asked if they would like to enter for a chance to win one of four \$25.00 gift cards. The name of the parent will be written on a piece of paper and entered in a locked raffle box with no other identifiable information or data. This box will remain locked at the Nemours duPont Pediatrics, St. Francis office. Drawings will take place at the end of December 2017 and the principal investigator will contact winning parents/caregivers by phone to pick-up the gift card at the Nemours duPont Pediatrics, St. Francis office.

No arrangement exists that would allow participants to share in any profit generated from this study or future research.

18. WILL I BE TOLD OF ANY NEW INFORMATION THAT MAY AFFECT MY WILLINGNESS TO STAY IN THE STUDY AND TO PERMIT MY CHILD TO STAY IN THE STUDY?

Any new information that may change your mind about participation in this study will be given to you. A committee called the Institutional Review Board (IRB) will review this study at least once per year. If the IRB finds that there is new information that you should know about while you and your child are taking part in this study, the IRB will ask the principal investigator to tell you about it. You may be asked to sign a new version of this form after discussing the new information with a member of the research team.

**19. WHAT INFORMATION ABOUT ME AND / OR MY CHILD WILL BE USED OR DISCLOSED?
(AUTHORIZATION TO USE AND / OR DISCLOSE PROTECTED HEALTH INFORMATION)**

Identifiable health information about you and / or your child will be used by Nemours researchers and will not be given to people outside of Nemours for this research.

Use of Health Information by Nemours Staff

The health information that will be used within Nemours includes all data collected for this study, as described in this form.

Your identity and your child's identity will be protected as much as possible. Nemours protects your and your child's health information by storing records in files or computers that can only be used by authorized Nemours staff.

Data collected will be entered in an Excel spreadsheet and coded with numbers to de-identify the information.

The people within Nemours that may use this health information include:

- The investigators listed on the first page of this permission form and their staff;
- The Nemours Institutional Review Board (IRB). (The IRB is a group of people that reviews research activities. The IRB is responsible for the safety and rights of research participants), and;
- Nemours internal audit staff.

Disclosure of Health Information to Others

No protected health information will be disclosed outside of Nemours.

Limits on Protection of Privacy and Confidentiality

Only health care organizations have to follow laws and rules about protecting the privacy of health information. If health information containing peoples' identities is given to other kinds of companies or organizations, they are not required by law to safeguard the privacy and confidentiality of that information. Nemours expects these companies and organizations to protect the privacy and confidentiality of research participants, but it is not possible for Nemours researchers to assure that this happens.

Government agencies that may look at records for this research study, including the above health information, include:

- The U.S. Food and Drug Administration
- The U.S. Department of Health and Human Services
- Other agencies of State and local government as required by law

The research results may be presented at scientific meetings or in print. Participants' identities will not be disclosed in those presentations.

20. SIGNATURES:

I am making a decision whether or not to consent to participate and to permit my child to participate in this study. I understand that my child may also have to agree to participate in the study before he / she will be allowed to be in this study. I have read, or had read to me in a language that I understand, all of the above. I have been given enough time to make this decision. I have asked questions and received answers about things I did not understand. I willingly consent to participate and give permission for my child to participate in this study. By signing this form, I am not giving up any rights to which I and my child are entitled under law.

I understand that:

- I can withdraw permission for my and my child's participation in this study and for the use and / or disclosure of PHI by contacting the person in charge of the study listed on the first page of this form.
- The use and / or disclosure of my and / or my child's PHI will stop after Nemours receives the withdrawal notice. Information that is used or disclosed before the withdrawal may still be used.
- Unless I and my child withdraw permission, the use and / or disclosure of PHI described in this form will expire when the research study is complete and analysis and publication have ended.
- I have the right to refuse to sign this permission / consent form.

- If I refuse to sign this permission / consent form, my child and I will not be allowed to be in this research study.
- I have the right to ask Nemours to tell me who has received my and / or my child's protected health information.
- I have the right to revoke my permission for the use and disclosure of my and / or my child's health information at any time, which would end my and my child's participation in this study.
- I will receive a signed and dated copy of this form.

Parent / Legal Guardian Signature Section

My signature indicates that:

- As his or her parent(s) or legally authorized representative(s), I(we) give my(our) permission for the minor child named below to participate in the research study described in this Parental Permission Form.
- I(We) give the researchers and Nemours permission to use and / or disclose my(our) child's individually identifiable health information for this research study as described in this form.

Name of Participant (**Print**)

Participant Date of Birth

Name of Parent / Legally Authorized Representative (**Print**)

Signature of Parent / Legally Authorized Representative
(#1)

Date

Check Relation to Participant: Parent Legally Authorized Representative

(Legally Authorized Representatives must have documented authority to give permission for a child's participation in a research study according to the laws of the State in which the treatment occurs.)

Second parent signature **N/A**

Do NOT check this box if the IRB determined that two (2) parent signatures are required as noted in the IRB final approval correspondence.

Name of Parent / Legally Authorized Representative (**Print**)

Signature of Parent / Legally Authorized Representative
(#2)

Date

Check Relation to Participant: Parent Legally Authorized Representative

(Legally Authorized Representatives must have documented authority to give permission for participation in a research study according to the laws of the State in which the treatment occurs.)

Study Team Member Signature Section

I, the undersigned, certify that to the best of my knowledge the parent(s) / legally authorized representative(s) signing this permission had the study fully and carefully explained and that she / he (they) understand(s) the nature, risks and benefits of their child's participation in this research study.

I, the undersigned, certify that the participant completed no research procedures for this study prior to signing this permission.

Name of Person Obtaining Permission (**Print**)

(Investigator or Designee)

Signature of Person Obtaining Permission

Date

(Investigator or Designee)

A copy of the signed form was provided to Parent(s) / Legally Authorized Representative(s)

Appendix B

Nemours Spanish Consent Form

Consentimiento Paterno de Nemours Y Formulario de Consentimiento Para Participar en Una Investigación

Nemours IC/PP Plantilla mayo 2017

Te han pedido que participes en un estudio de investigación con su hijo(a). Esta forma explica la investigación, sus derechos y los derechos de su hijo(a) como participantes en esta investigación, y cualquier responsabilidad que tendrá como resultado de su participación y la de su hijo(a). Usted debería de entender el estudio de investigación antes de consentir estar en la investigación y permita que su hijo(a) participe. **Usted va a recibir una copia de esta forma. Lea cuidadosamente esta forma. También puede platicar acerca del estudio de investigación con sus familiares y amigos. Un miembro de la investigación responderá cualquier pregunta que usted tenga antes que tome una decisión.**

1. ¿CUAL ES EL TITULO DEL ESTUDIO?

ALFABETISMO EN SALUD DE PADRE/ CUIDADOR HISPANO Y DOMINIO DEL IDIOMA INGLES: VARIABLES QUE AFECTAN LA UTILIZACION DEL SERVICIO DE URGENCIAS PEDIATRICO.

2. ¿QUIEN ESTA A CARGO EN EL ESTUDIO EN NEMOURS?

Si tiene una pregunta, queja, o algún problema relacionado con el estudio, puede llamar al investigador a cualquier hora en los números alistados debajo.

Nemours – WIL	
Investigador Principal	Sandy A. Ramirez Sanchez, MSW
Co-Investigador(es)	Cheyenne Hughes-Reid, PhD Tutor
Coordinador(es) Del Estudio	
Dirección	701 N. Clayton Street, Suite 400 Wilmington, De 19805
Teléfono Durante el Horario Laboral	302-421-9706 610-633-6294

Teléfono Después Del Horario Laboral	
Larga Distancia	1-800-SOS-KIDS or 1-800-767-5437

3. ¿A QUIEN DEBERIAN CONTACTAR LOS PARTICIPANTES DEL ESTUDIO SOBRE SUS DERECHOS?

Si tiene una pregunta sobre sus derechos o las de su hijo(a) como participantes del estudio, que debería hacer si usted o su hijo(a) se lastiman, si le gustaría dar su opinión u obtener información, o si no puede comunicarse con el investigador o si le gustaría hablar con alguien que no está involucrado con el estudio, podrá comunicarse con las personas alistadas debajo.

Presidente, Nemours IRB 1 en 302-651-5970
 Director, Oficina de Nemours de protección a sujetos humanos at 302-298-7613
 Correo electrónico: NOHSP@nemours.org

4. ¿CUAL ES EL PROPOSITO DE ESTE ESTUDIO?

El propósito de este estudio es explorar el alfabetismo en salud de padres/cuidadores Hispanos y la utilización de servicios de urgencias pediátrico para niños/niñas de recién nacidos a 10 años de edad de una sola oficina de consultorio de atención primaria pediátrica en Wilmington, Delaware. El dominio del idioma ingles también será medido para determinar si el dominio del idioma ingles es un variable moderador para la utilización de servicios de urgencias pediátrico en niños/niñas de padres/cuidadores Hispanos.

5. ¿QUIEN PARTICIONA O ESTA PAGANDO POR ESTE ESTUDIO?

Sandy A. Ramirez Sánchez, MSW es la patrocinadora de este estudio. Nadie le pagará a Nemours por el costo de conducir este estudio; este estudio es parte de los requisitos para obtener el doctorado en trabajo social (DSW) de la investigadora.

6. ¿QUIEN PUEDE PARTICIPAR?

Un padre/cuidador hispano de por lo menos 18 años de edad, que habla español o inglés, con tutela legal del niño(a), de 10 años de edad o menos, visto en Nemours duPont Pediatrics, St. Francis para cuidado de atención primaria y no está programado para una cita como nuevo paciente o una cita médica de urgencia.

7. ¿CUANTAS PERSONAS PODRAN PARTICIPAR EN EL ESTUDIO?

Esperamos ingresar 360 participantes de Nemours duPont Pediatrics, St. Francis.

8. ¿CUANTO TIEMPO DURARA LA PARTICIPACION DE ESTE ESTUDIO?

Completar la encuesta demográfica y medir la alfabetización en salud usando el Newest Vital Sign (NVS) tomara el promedio de 15-20 minutos. El investigador principal revisara el expediente medico electrónico del niño(a) en otro momento. Revisión del expediente médico tomara el promedio de 15-30 minutos. No será necesario regresar para una segunda visita.

9. ¿CUALES SON LOS PROCEDIMIENTO DEL ESTUDIO?

A) El padre/cuidador tendrá que completar y firmar este formulario de consentimiento y completar lo siguiente:

B) El padre/cuidador se le pedirá completar un cuestionario demográfico conteniendo 11 preguntas que se pide al padre/cuidador la fecha de nacimiento, parentesco al niño(a), lugar de nacimiento del padre/cuidador, el número de años que el padre/cuidador ha vivido en los Estado Unidos, lugar de nacimiento de la madre y padre del padre/cuidador, genero, estado civil, estado de empleo, último año de escuela completado, que tan bien habla inglés, y que tan bien lee inglés.

C) El padre/cuidador entonces tendrá que completar el Newest Vital Sign (NVS) para medir la alfabetización de salud. El NVS es una herramienta válida que mide la alfabetización de salud usando una etiqueta nutricional de helado y consiste de 6 preguntas que toman aproximadamente 3 minutos para administrar por el investigador principal.

D) El investigador principal revisara el expediente médico electrónico (AME) del niño(a), con consentimiento del padre/cuidador, para visitas al departamento de emergencia en los últimos 365 días a partir de la fecha de este consentimiento informado. El número de visitas al departamento de emergencia serán contados en los últimos 365 días, y el numero de visitas donde no se admite al hospital.

E) Padres/cuidadores serán reclutados para este estudio por medio de muestra de conveniencia en Nemours duPont Pediatrics, St. Francis. El investigador principal revisara la lista de pacientes del día y se acercara a padres/cuidadores elegibles para el estudio cuando lleguen para su cita referente a este estudio. Todos los datos colectados serán completados en un cuarto privado dentro de la oficina de Nemours duPont Pediatrics, St. Francis antes o después de que el niño(a) fue visto para su cita médica.

10. ¿CUALES SON LOS RIESGOS POSIBLES DE ESTAR EN ESTE ESTUDIO?

Cualquier tipo de investigación puede tener algunos riesgos (como cosas que puedan enfermarte a ti o a tu hijo(a), se sientan incómodos, o se lastimen).

Los riesgos con más probabilidad que sucedan se alistan debajo. Además, hay oportunidad de otros riesgos que casi nunca pasan, o riesgos desconocidos.

Algunos padres/cuidadores se pueden sentir avergonzados o apenados de divulgar su dominio del idioma inglés, o de tener probado su alfabetización en salud, especialmente si el padre/cuidador tiene bajo la alfabetización de salud. En un esfuerzo para minimizar los sentimientos de vergüenza o pena, toda información colectada será en privado. Si un padre/cuidador sienten que necesitan apoyo adicional, se le proveerá con información de servicios bilingües para la salud mental en la comunidad.

También existe el riesgo de divulgar su identidad y posible pérdida de privacidad; sin embargo, se tomarán todas las precauciones para garantizar que esto no ocurra.

11. ¿CUALES SON LOS BENEFICIOS POSIBLES DE PARTICIPAR EN ESTE ESTUDIO?

No hay provechos directos de participar en este estudio.

Sin embargo, los resultados potencialmente pueden ayudar a identificar si la alfabetización de salud es un problema que el personal médico en Nemours duPont Pediatrics, St. Francis necesita tomar en consideración cuando se comunican con los pacientes y familias verbalmente y por escrito.

12. ¿QUE SUCEDE SI HAY UN PROBLEMA O SE LASTIMAN COMO RESULTADO DE LOS PROCEDIMIENTOS DE ESTE ESTUDIO?

Nemours le asegura que usted o su hijo(a) recibirá tratamiento médico, si es necesario, si es relacionado por el estudio. Ni Nemours ni el doctor de este estudio tienen un programa para cubrir los gastos médicos. Si usted o su hijo(a) tienen seguridad médica, se podrá, o no se podrá cubrir los gastos médicos si se lastiman por este estudio. Si su seguro no paga, o si usted o su hijo(a) no tienen seguro, entienda que usted es responsable por cubrir sus gastos médicos.

Si piensa que usted o su hijo(a) se han lastimado por medio de este estudio o si un problema ha ocurrido por medio de este estudio, debería decirle de inmediato a un doctor de esta investigación. El doctor de este estudio o investigadores podrán decirle lo que tiene que hacer. Los nombres y los teléfonos de los doctores de este estudio están en la primera página de esta forma.

Los ayudantes de este estudio están disponibles lunes a viernes de 8:00am a 5:00pm. Durante estas horas podrá llamar al 302-421-9700- para consejo médico.

Durante el anochecer, fin de semana, y durante días feriados, debería llamar al 302-421-9700. Se contactará con la enfermera de Kids Health on-call.

13. ESTAR EN ESTE ESTUDIO ¿ES VOLUNTARIO?

Estar en este estudio es totalmente voluntario. Cualquiera que participe en este estudio puede parar de participar de él en cualquier momento. No habrá un cambio médico en su tratamiento si desean participar o dejar de participar en este estudio. Nadie se enojará con usted o su hijo(a), o se le tratará diferente al participar o no en este estudio. Pero este estudio requiere la participación de ambos de ustedes; si desea dejar de participar en este estudio, la participación de su hijo también terminará.

Si termina de participar en este estudio, usted y su hijo(a) pueden continuar su tratamiento médico con su o el doctor(a) de su hijo(a), o puede continuar su atención medica con otro doctor(a) que usted elija.

En caso que usted o su hijo(a) deje de participar en el estudio, el investigador principal puede pedir su permiso para hacer un seguimiento del estudio, y todo dato clínico colectado en relación a el estudio se puede continuar de colectarse del archivo medico de su hijo(a).

Puedes pedir que el investigador destruya su información o muestras y la de su hijo(a). Su petición debe ser por escrito. El investigador le dirá si esto es posible. Puede haber razones legales para mantener información de usted y/o su hijo(a).

Si decide darse de baja del estudio, no hay consecuencias adversas previsibles.

14. ¿QUE OTRAS OPCIONES TENGO APARTE DE PARTICIPAR EN ESTE ESTUDIO?

Usted y su hijo(a) pueden reusar participar en este estudio. Podrá haber otras obras de investigación o tratamientos que puede considerar. Estas opciones incluyen:

Una investigación acerca del alfabetismo de salud en Nemours en el futuro o por medio de otro sistema de cuidado de salud u organización. El investigador principal no está actualmente consiente de ningún otro estudio de alfabetización de salud en esta área.

15. ¿PUEDEN LOS INVESTIGADORES DE ESTE ESTUDIO REMOVER A ALGUIEN DEL ESTUDIO?

Si el participante no alcanza los requisitos de este estudio como la edad del padre/cuidador (por lo menos 18 años o más), nacionalidad, tener un niño(a) de 10 años de edad o más joven, y no tiene custodia legal no será permitido participar en el estudio.

16. ¿CUAL ES EL COSTO DE PARTICIPAR EN ESTE ESTUDIO?

No se les añadirá algún costo a padres/cuidadores que participen en este estudio. Costos indirectos incluye tiempo antes o después de la cita médica programada para el niño(a) para completar este estudio.

17. ¿SE NOS PAGARA POR PARTICIPAR EN ESTE ESTUDIO?

Después de proveer consentimiento, completar el cuestionario demográfico y el Newest Vital Sign (NVS), se le preguntara al padre/cuidador si gustaría entrar para tener la oportunidad de ganar una de cuatro tarjetas de regalo de \$25.00. El nombre del padre/cuidador será escrito en un pedazo de papel e ingresado en una caja de rifa cerrada sin ninguna otra información identificable o datos. Esta caja permanecerá cerrada en la oficina de Nemours duPont Pediatrics, St. Francis. El sorteo será al final de diciembre 2017 y la investigadora principal contactará a los padres/cuidadores que ganen por teléfono para recoger la tarjeta de regalo en la oficina de Nemours duPont Pediatrics, St. Francis.

No existe ningún acuerdo que permitiría a los participantes compartir en cualquiera ganancia generada por parte de este estudio o futuros estudios.

18. ¿SE ME NOTIFICARA DE CUALQUIERA NUEVA INFORMACIÓN QUE PUDIERA AFECTAR MI VOLUNTAD PARA PERMANECER EN ESTE ESTUDIO Y PERMITIR QUE MI HIJO(A) PERMANEZCA EN EL ESTUDIO?

Cualquiera información nueva que pudiera cambiar su pensar referente a participar en este estudio se le dará. El comité llamado Institutional Review Board (IRB) revisara este estudio por lo menos una vez al año. Si el IRB encuentra que hay información nueva que usted debería saber mientras usted y su hijo(a) toman parte en este estudio, el IRB le pedirá al investigador principal del estudio que se lo comunique. Se le podría volver a solicitar que firme una nueva versión de esta forma después de discutir la nueva información con un miembro del equipo del estudio.

19. ¿QUÉ INFORMACIÓN SOBRE MI O MI HIJO (A) SERÁ USADA O DIVULGADA? (AUTORIZACIÓN PARA USAR Y/O DIVULGAR INFORMACIÓN PROTEGIDA DE SALUD).

Información de salud identificable acerca de usted y/o su niño(a) será utilizada por los investigadores de Nemours y no será dada a personas fuera de Nemours para esta investigación.

El uso de información de salud por parte del personal de Nemours.

La información de salud que se usara dentro de Nemours incluye todos los datos colectados para este estudio como se describe en este formulario.

Su identidad y la identidad de su hijo(a) serán protegidas lo más posible. Nemours protege la información de salud de usted y su hijo(a) por almacenamiento de en archivos o computadoras que solo puede usar personal autorizados por Nemours.

Datos coleccionados será ingresados en una hoja de cálculo de Excel y codificado con números para des- identificar la información.

Las personas dentro de Nemours que pueden usar esta información de salud incluyen:

- Los investigadores listados en la primera página de este formulario de consentimiento y su personal;
- El Institutional Review Board (IRB) de Nemours. (El IRB es un grupo de gente que revisa actividades de investigaciones. El IRB es responsable por la seguridad y derechos de participantes en el estudio), y;
- Personal interna de auditoría de Nemours.

Revelación de información de salud a otros

Información identificable no se revelará fuera de Nemours.

Límites de protección de Privacidad y Confidencialidad

Solamente organizaciones de cuidado de salud tienen que seguir las leyes y reglas sobre la protección de privacidad de información de salud. Si se le da información de salud que contiene las identidades de personas a otros tipos de compañías e organizaciones, ellos no están requeridos por ley a proteger la privacidad y confidencialidad de esa información. Nemours espera que estas compañías y organizaciones protejan la privacidad y confidencialidad de los participantes en investigaciones, pero no es posible que los investigadores de Nemours aseguren que esto suceda.

Las agencias gubernamentales podrían ver los registros de este estudio de investigación, incluyendo la información de salud anteriormente, incluyen:

- La Administración de Alimentos y Medicamentos de U.S
- El Departamento de Salud y Servicios Humanos de U.S
- Otros organismos del Estado y de los gobiernos locales como exige la ley

Los resultados del estudio podrían ser presentados en reuniones científicas o por escrito. No se divulgará las identidades de los participantes en esas presentaciones.

20. FIRMAS

Estoy tomando una decisión de dar consentimiento o no para participar y permitir que mi hijo (a) participe en este estudio. Entiendo que mi hijo(a) también pueda tener que estar de acuerdo en participar en este estudio antes que él/ella se le permita participar en el estudio. Yo he leído, o se me ha leído en un idioma que entiendo, todo lo indicado aquí. Se me ha dado suficiente tiempo para tomar esta decisión. Yo he preguntado preguntas y he recibido respuestas sobre cosas que no entendía. De buena voluntad yo doy consentimiento para participar y doy permiso para que mi hijo (a) participe en este estudio. Por medio de mi firma en esta forma, no estoy rindiendo ninguno de mis derechos o los de mi hijo(a) a los que somos intitulados bajo la ley.

Yo entiendo que:

- Yo puedo retirar el permiso de participación mía y mi hijo(a) en este estudio y para el uso y/o revelación de información de salud protegida contactando a la persona encargada del estudio que esta listada en la primera página de esta forma.
- El uso y/o revelación de información de salud protegida de mi y/o mi hijo(a) se detendrá después de que Nemours reciba la notificación de retiro. Información usada y/o revelada antes del retiro se podría continuar usando.
- A menos que yo y mi hijo(a) retiramos permiso, el uso y/o revelación de información de salud protegida descrito en esta forma se expira cuando el estudio sea completado y analizado y la publicación ha terminado.
- Tengo el derecho de negar firmar este permiso/formulario de consentimiento.
- Si niego firmar este permiso/formulario de consentimiento, mi niño(a) y yo no seremos permitidos tomar parte en este estudio.
- Yo tengo el derecho de preguntar a Nemours quien ha recibido mi información de salud protegida o la de mi niño(a).
- Yo tengo el derecho de revocar mi permiso del uso y revelación de mí información de salud y la de mi niño(a) en cualquier momento, cual terminaría mi participación y la de mi niño(a) en este estudio.
- Yo voy a recibir una copia firmada y fechado de esta forma.

Sección de firma del Padre/Custodio Legal

Mi firma indica que:

• Como su padre(s) o representate(s) legalmente autorizado(s), yo (nosotros) doy/damos permiso para que el/la niño/niña menor de edad nombrado/nombrada abajo participe en este estudio descrito en este formulario de consentimiento paterno y doy consentimiento para mi participación en el estudio descrito en esta forma.

• Yo (nosotros) doy/damos a los investigadores y Nemours permiso para usar y/o revelar información de salud identificable mía y/o de mi hijo(a), para este estudio, como se describe en esta forma.

Nombre del Participante (Imprimir)

Fecha de nacimiento del Participante

Nombre del Padre/Representante legalmente autorizado (**Imprimir**)

Firma del Padre/ Representante legalmente autorizado

Fecha

(#1)

Indique relación al participante: Padre Representante legalmente autorizado

(Representante legalmente autorizado tiene que tener la autoridad de dar permiso documentado para que el niño/niña participe en este estudio de acuerdo con las leyes en el estado en donde se le da el tratamiento.)

Sección de firma del segundo padre No Aplica

No haga un cheque en esta caja si el IRB determino que dos (2) firmas de padres son requeridas como se ha señalado en la correspondencia de aprobación final del IRB.

Nombre del Padre/Representante legalmente autorizado (**Imprimir**)

Firma del Padre/ Representante legalmente autorizado Fecha

(#2)

Indique relación al participante: Padre Representante legalmente autorizado

(Representante legalmente autorizado tiene que tener la autoridad de dar permiso documentado para que el niño/niña participe en este estudio de acuerdo con las leyes en el estado en donde se le da el tratamiento.)

Sección de Firma del Miembro del Equipo de Estudio

I, the undersigned, certify that to the best of my knowledge the parent(s) / legally authorized representative(s) signing this permission had the study fully and carefully explained and that the parent(s) / legally authorized representative(s) understand(s) the nature, risks and benefits of participation in this research study.

I, the undersigned, certify that the participant completed no research procedures for this study prior to signing this permission.

Name of Person Obtaining permission (**Print**)

(Investigator or Designee)

Signature of Person Obtaining Permission

(Investigator or Designee)

Date

A copy of the signed form was provided to Parent (s)/Legally Authorized Representative (s)

Appendix C

English Demographic Questionnaire

Demographic Questionnaire

Please circle or fill in your answer below.

1. Parent/Caregiver's date of birth: _____

2. Parent/Caregiver's relation to the child seen today:
 - a. Biological Mother
 - b. Biological Father
 - c. Maternal Grandmother
 - d. Maternal Grandfather
 - e. Paternal Grandmother
 - f. Paternal Grandfather
 - g. Aunt
 - h. Uncle
 - i. Other (please write): _____

3. Parent/Caregiver's Place of Birth:
 - a. Please write: _____

4. Parent/Caregiver: How many years have you lived in the United States?
 - a. _____

5. Parent/Caregiver: What country was your mother and father born?
 - a. Mother: _____
 - b. Father: _____

6. Parent/Caregiver's Gender:
 - a. Male
 - b. Female
 - c. Other (please write): _____

7. Parent/Caregiver's marital status:
 - a. Divorced
 - b. Living with partner
 - c. Long Term Partner (not married, not living together)

- d. Married
 - e. Domestic Partnership/Civil Union
 - f. Single
 - g. Separated
 - h. Widowed
8. Parent/Caregiver: Are you employed?
- a. No
 - b. Yes-Part Time
 - c. Yes-Full Time
9. Parent/Caregiver: What is the last year of school you completed? :
- a. Sixth grade or less
 - b. Seventh grade
 - c. Eighth grade
 - d. Ninth grade
 - e. Tenth grade
 - f. Eleventh grade
 - g. High School Diploma
 - h. Some college
 - i. Bachelor's degree
 - j. Graduate degree
 - k. Associate's Degree
 - l. Other:_____

10. Parent/Caregiver:

I speak English well

Strongly Disagree--Disagree--Mildly Disagree--Mildly Agree--Agree--Strongly Agree

1 2 3 4 5 6

11. Parent/Caregiver:

I read English well

Strongly Disagree---Disagree---Mildly Disagree---Mildly Agree---Agree---Strongly Agree

1 2 3 4 5 6

Appendix D

Spanish Demographic Questionnaire

Cuestionario Demográfico

Favor de circular o llenar con su respuesta.

1. Fecha de nacimiento del padre/cuidador: _____
2. Relación del padre/cuidador del niño/a al que se va atender hoy:
 - a. Madre biológica
 - b. Padre biológico
 - c. Abuela Materna
 - d. Abuelo Materno
 - e. Abuela Paterna
 - f. Abuelo Paterno
 - g. Tía
 - h. Tío
 - i. Otro (favor de escribir): _____
3. Lugar de Nacimiento del padre/cuidador:
 - a. Favor de escribir: _____
4. Padre/cuidador: ¿Cuántos años ha vivido en Estados Unidos?
 - a. _____
5. Padre/cuidador: ¿En qué país nació su madre y padre?
 - a. Madre: _____
 - b. Padre: _____
6. Genero del padre/cuidador:
 - a. Hombre
 - b. Mujer
 - c. Otro (favor de escribir): _____
7. Estado civil del padre/cuidador:
 - a. Divorciado/a
 - b. Viviendo con mi pareja
 - c. Pareja de largo plazo (no casado/a, no viven juntos)
 - d. Casado/a
 - e. Pareja domestica/Unión civil

- f. Soltero/a
- g. Separado/a
- h. Viudo/a

8. Padre/Cuidador: ¿Tiene trabajo?

- a. No
- b. Si-Medio tiempo
- c. Si-Tiempo completo

9. Padre/Cuidador: ¿Cuál es el ultimo año de escuela que completo?

- a. Sexto grado o menos
- b. Séptimo grado
- c. Octavo grado
- d. Noveno grado
- e. Décimo grado
- f. Undécimo grado
- g. Diploma de escuela secundaria
- h. Algunos años de Universidad
- i. Diploma de Universidad (Licenciatura/Bachillerato)
- j. Diploma Posgrado
- k. Licenciatura Asociados
- l. Otro: _____

10. Padre/Cuidador:

Yo hablo bien ingles

Muy en Desacuerdo--Desacuerdo-- Moderadamente en Desacuerdo--Moderadamente en Acuerdo--De Acuerdo--Totalmente de acuerdo

1 2 3 4 5 6

11. Padre/Cuidador:

Yo leo bien ingles

Muy en Desacuerdo--Desacuerdo-- Moderadamente en Desacuerdo--Moderadamente de Acuerdo--De Acuerdo--Totalmente de acuerdo

1 2 3 4 5 6

Appendix E

The Newest Vital Sign

Nutrition Facts			
Serving Size			½ cup
Servings per container			4
<hr/>			
Amount per serving			
Calories	250	Fat Cal	120
<hr/>			
			%DV
Total Fat	13g		20%
Sat Fat	9g		40%
Cholesterol	28mg		12%
Sodium	55mg		2%
Total Carbohydrate	30g		12%
Dietary Fiber	2g		
Sugars	23g		
Protein	4g		8%

*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

Appendix F

The Newest Vital Sign Questions and Score Sheet



Score Sheet for the Newest Vital Sign Questions and Answers

READ TO SUBJECT:

This information is on the back of a container of a pint of ice cream.

1. If you eat the entire container, how many calories will you eat?
Answer: 1,000 is the only correct answer

2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?
Answer: Any of the following is correct: 1 cup (or any amount up to 1 cup), half the container. Note: If patient answers "two servings," ask "How much ice cream would that be if you were to measure it into a bowl?"

3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?
Answer: 33 is the only correct answer

4. If you usually eat 2,500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?
Answer: 10% is the only correct answer

READ TO SUBJECT:

Pretend that you are allergic to the following substances: penicillin, peanuts, latex gloves, and bee stings.

5. Is it safe for you to eat this ice cream?
Answer: No

6. (Ask only if the patient responds "no" to question 5): Why not?
Answer: Because it has peanut oil.

ANSWER CORRECT?

ANSWER CORRECT?	
yes	no

Number of correct answers:

Interpretation

- Score of 0-1 suggests high likelihood (50% or more) of limited literacy.**
- Score of 2-3 indicates the possibility of limited literacy.**
- Score of 4-6 almost always indicates adequate literacy.**

Appendix G

The Newest Vital Sign-Spanish

Datos nutricionales

Tamaño de la porción 1/2 taza
Porciones por envase 4

Cantidad en cada porción
Calorías 250 Calorías de grasa 120

% del valor diario (VD)*

Grasa total 13 g 20%

Grasas saturadas 9 g 40%

Grasas *trans* 0 g

Colesterol 28 mg 12%

Sodio 55 mg 2%

Total de carbohidratos 30 g 12%

Fibra dietética 2 g

Azúcares 23 g

Proteína 4 g 8%

*El porcentaje de valores diarios (VD) se basa en una dieta de 2,000 calorías. Sus valores diarios pueden ser mayores o menores dependiendo de las calorías que necesite.

Ingredientes: Crema, leche descremada, azúcar líquida, agua, yemas de huevo, azúcar morena, grasa de leche, aceite de cacahuete (maní), azúcar, sal, carragenano, extracto de vainilla.

Appendix H

The Newest Vital Sign Questions and Score Sheet-Spanish



Hoja de Resultados para el Nuevo Signo Vital Preguntas y Respuestas

LEA AL SUJETO DEL ESTUDIO:

Esta información aparece al reverso de un envase de helado.

1. Si consume todo el helado en el envase, ¿cuántas calorías habrá consumido?
Respuesta: 1,000 es la única respuesta correcta

2. Si le permiten consumir 60 gramos de carbohidratos como refrigerio, ¿cuánto helado puede consumir?
Respuesta: Cualquiera de las siguientes es correcta: 1 taza (o cualquier cantidad hasta 1 taza), la mitad del envase". Nota: si el sujeto del estudio responde "dos porciones", pregunte "¿Cuánto helado sería si lo midiera para ponerlo en un tazón?"

3. Su médico le aconseja reducir la cantidad de grasa saturada en su dieta. Usted normalmente consume 42 gramos de grasa saturada al día, que incluyen una porción de helado. Si deja de consumir helado, ¿cuántos gramos de grasa saturada consumiría cada día?
Respuesta: 33 gramos es la única respuesta correcta

4. Si normalmente consume 2,500 calorías al día, ¿qué porcentaje de su valor diario de calorías habrá consumido si consume una porción?
Respuesta: 10% es la única respuesta correcta

LEA AL SUJETO DEL ESTUDIO:

Imagínese que es alérgico/a a las siguientes sustancias: penicilina, cacahuete (maní), guantes de látex y picaduras de abeja.

5. ¿Es seguro consumir este helado?
Respuesta: No

6. (Pregunte sólo si responde "no" a pregunta 5): ¿Por qué no?
Respuesta: Porque tiene aceite de cacahuete (maní)

¿RESPUESTA CORRECTA?

sí	no

Número de respuestas correctas:

Interpretación

Resultado de 0-1 sugiere alta probabilidad (50% o más) de alfabetización limitada.
Resultado de 2-3 indica la posibilidad de alfabetización limitada.
Resultado de 4-6 casi siempre indica alfabetización adecuada.



Vita

Sandy Anhai Ramirez Sanchez attended Kennett High School in Kennett Square, Pennsylvania. In 2004, she began attending Kutztown University of Pennsylvania and graduated in 2008 with a Bachelor of Social Work (BSW) degree. Immediately after obtaining her BSW, Sandy continued at Kutztown University of Pennsylvania and completed her Master of Social Work (MSW) degree in 2009. During the following years, she was employed as a supports coordinator and crisis interventionist in Berks County, PA. Sandy transitioned to a social work position in pediatric primary care in 2014 where she currently remains. In August, 2015, she entered the joint Doctor of Social Work program with Kutztown University of Pennsylvania and Millersville University of Pennsylvania.

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This manuscript was typed by the author.