University of Louisville

ThinkIR: The University of Louisville's Institutional Repository

Electronic Theses and Dissertations

5-2015

Impact of numeracy on parental self-efficacy and treatment outcome of children on complex diets.

Diana Cardina Pantalos
University of Louisville

.

IMPACT OF NUMERACY ON PARENTAL SELF-EFFICACY

AND TREATMENT OUTCOME OF CHILDREN ON COMPLEX DIETS

By

Diana Cardina Pantalos
Bachelor of Science, Ohio State University, 1975
Master of Science, Ohio State University, 1977

A Dissertation
Submitted to the Faculty of the
School of Public Health and Information Sciences of the University of Louisville
in Partial Fulfillment of the Requirements
for the Degree of

Doctor of Philosophy in Public Health Science

Department of Health Promotion and Behavioral Sciences
University of Louisville
Louisville, KY

May, 2015

IMPACT OF NUMERACY ON PARENTAL SELF-EFFICACY

AND TREATMENT OUTCOME OF CHILDREN ON COMPLEX DIETS

By

Diana Cardina Pantalos
B.S., Ohio State University, 1975
M.S., Ohio State University, 1977

A Dissertation Approved on

April 8, 2015

by the following Dissertation Committee:

Richard W. Wilson, DHSc, MPH
Dissertation Chair

Paul J. Klein, PhD

David J. Roelfs, PhD

Michael L. Rowland, PhD

DEDICATION

This dissertation is dedicated to my father,

James A. Cardina

ACKNOWLEDGMENTS

Many people were instrumental in the planning, implementation and completion of this dissertation. My committee was a rich source of experience and expertise, but also enthusiasm: I would like to thank Chair Dr. Richard Wilson for his endless optimism, Dr. David Roelfs for his patience in teaching, Dr. Paul Klein for his excitement over mathematics, and Dr. Michael Rowland for his insights.

Next I would like to honor the parents who participated in the study, and their families who made data collection possible. I particularly appreciate the leaders and members of the community organizations who welcomed me to their events, including the Tennessee PKU Association, the PKU Organization of Illinois, the Indiana PKU and Allied Disorders Organization, and the Ohio Chapter of the Mid-Atlantic Connection for PKU and Allied Disorders. Representatives of Vitaflo USA and Nutricia North America helped me connect with these organizations.

The clinicians and staff at the University of Kentucky were generous in helping me recruit their patients, as was the nutritionist at Indiana University Medical Center. I am thankful for these individuals as well as their counterparts at the seven other clinics around the region who retrieved data from patients' medical records. I was fortunate that the Clinical Genetics program at the University of Louisville was willing to accommodate my needs for patient access. I especially appreciate Dr. Alexander Asamoah for his advice, Dr. Lonnie Sears for training and oversight of the use of the WRAT-4, and Carol Hoffman, APRN for flexibility in the clinic environment.

The University of Louisville Wendy L. Novak Center for Diabetes Care was instrumental to the completion of this research. Dr. Kupper Wintergerst and Heather Rush APRN contributed to the project by promoting it among their patients, and guiding the data collection process. Thank you to the staff of the Pediatric Endocrinology clinic who coordinated the patient flow in the clinic.

Finally, I send gracious thanks to my husband who provided valuable perspective on conducting research and shared the ups and downs of the process, to my children who were a source of humor and support, to my brother John who understood why this was important to me, and to friends who believed in me and believed this endeavor was worthwhile.

ABSTRACT

IMPACT OF NUMERACY ON PARENTAL SELF-EFFICACY

AND TREATMENT OUTCOME OF CHILDREN ON COMPLEX DIETS

Diana Cardina Pantalos

April 8, 2015

Health numeracy, a counterpart to health literacy, can be a mediator of health disparities. This study analyzed the impact of both cognitive and affective numeracy on the pathway linking health behavior to health outcomes, and the role of self-efficacy in this relationship, based on the Health Belief Model. The context was parental management of children's complex diets that require numerical calculations.

Parents of children ages 12 months to 12 years with type 1 diabetes (T1D) or phenylketonuria (PKU) were recruited at clinics or community events in east-central states. Ninety-eight participants completed a standardized test of math skills, an instrument to assess attitudes and emotions towards mathematics in daily life, and a questionnaire on parental self-efficacy of caring for a child with T1D or PKU. Health outcome was evaluated via hemoglobin A1c or blood levels of phenylalanine. Engagement was measured by number of blood levels taken during glucose or phenylalanine monitoring, compared to clinic recommendations.

Factor analysis indicated affective numeracy was a significant component of the overall variable numeracy. Structural equation modeling did not support a relationship between any variable and health outcome, although bivariate analysis suggested significant relationships between poor math skills, low self-efficacy, less engagement, low income, less education, or more years on the diet, and poor metabolic control. In pathway analysis, cognitive numeracy had a strong positive relationship with engagement, while affective numeracy had an equal but negative predictive effect. Adjustments to the model identified education as the ultimate driver of the relationship. Parental self-efficacy was not a mediator between numeracy and health outcomes or engagement. The relationship between self-efficacy and engagement was strongly influenced by other pathway variables, and parental self-efficacy was significantly lower when the child had been on the diet for a longer time.

This study asserts the importance of affective component of numeracy along with cognitive skills, and offers a validated instrument for assessment. Treatment programs for PKU and T1D should recognize that parents with lower numeracy skills and discomfort with math are at risk for less engagement. Further research is needed to clarify the path by which numeracy impacts health outcomes.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

CHAPTER I

INTRODUCTION

Two infants are born on the same day, into two different families in two different communities. Beyond genetics, what determines the difference between the two children's short and long-term health outcomes? In public health, health disparities are examined on a larger scale, but the same question applies: what factors impact health-related quality of life and well-being? Healthy People, a set of 10-year national health and disease prevention goals set by the United States Department of Health and Human Services, has included health disparities as an overarching goal for more than two decades. In Healthy People 2020, health disparity is defined as “a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage." (U.S. Department of Health & Human Services, 2011a).

Determinants of health fall into broad categories of policy, biology and genetics, individual behavior, social factors, and physical environment (U.S. Department of Health & Human Services, 2011a). Within these categories, characteristics such as education, socioeconomic status, and place of residence are a few of the more specific qualities that impact health outcomes. Health promotion and intervention require an understanding of how well-being may be enhanced or undermined by such factors. The mediators and moderators of the pathway between determinants of health and outcomes are vast, and research is needed to measure and explain them.

Health Literacy

Health literacy is one of the mediators of health disparities (Abrams, Klass, & Dreyer, 2009; Yin et al., 2009; Yin et al., 2012). It has been recognized as a public health issue (Baur, 2010) and an ethical imperative (Gazmararian, Curran, Parker, Bernhardt, & DeBuono, 2005), (Nelson, Schwartzberg, & Vergara, 2005). The conceptualization and understanding of health literacy has evolved quickly in its relatively short history.

Health literacy as a national concern has its roots in the emergence of adult literacy as a public policy issue in the 1980's (N. Berkman, Davis, T., McCormack, L., 2010). In 1993, a large national literacy survey, the National Assessment of Adult Literacy (NAAL), revealed inadequate skills among a surprising 90 million Americans (Kirsch, 1993). Williams and colleagues first measured health literacy, in a hospital setting, and found one-third of English-speaking patients unable to read basic health-related materials (M. V. Williams, Parker, Baker, & et al., 1995; M. V. Williams, Parker, R., Baker, D., 1995), which inspired further research and instrument development (D. W. Baker, Williams, Parker, Gazmararian, & Nurss, 1999). When a ten-year follow up of the NAAL was planned for 2003, Healthy People 2010 requested the addition of health content, and the relationship between low literacy and poor health has become a common topic in the medical literature and government reports (N. Berkman, Davis, T., McCormack, L., 2010; Berkman N.D., 2010).

Definitions of health literacy.

Early definitions of health literacy were centered on individual capacities, such as a set of skills required to function as a consumer in the health care environment (Ad Hoc Committee on Health Literacy, 1999; Ad Hoc Committee on Health Literacy for the Council on Scientific & American Medical, 1999). A widely used definition is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Ratzan, 2000). This definition was adopted by Healthy People 2010 (U.S. Department of Health & Human Services, 2000), the Institute of Medicine (Institute of Medicine, 2004) and the Agency for Healthcare Research and Quality (N. D. Berkman, Dewalt, D.A., Pignone, M.P., et al., 2004), and is used in this dissertation. Others consider health literacy as a dynamic relationship between the individual and the health care system providing care (D.W. Baker, 2006). In Healthy People 2020, health literacy is part of health communication skills needed to manage health issues, which include ability and experience using the Internet (U.S. Department of Health & Human Services, 2013).

Recently health literacy has also been viewed in a broader context, such as an asset in a community's ability to navigate and improve health care systems (Nutbeam, 2008). The World Health Organization (WHO) sees health literacy in the domain of health promotion, since improving access to health information and the ability to use it result in empowerment at the community level (World Health Organization, 2009). While this dissertation studies health literacy on the individual level, this wider view also acknowledges the place of health literacy on the pathway between determinants of health and health outcomes.

Prevalence of low health literacy.

In the 2003 NAAL assessment of abilities to read health-related passages and instructions in English, 36% of U.S. adults had limited health literacy: 22% had Basic and 14% Below Basic (National Center for Educational Statistics, 2003). Another 5% of the US population is not literate in English at all. Low health literacy contributes to health disparities in vulnerable populations, including older adults, immigrants, minorities, and low-income individuals (Glassman, 2013). In addition to individual costs, the national economic impact of low health literacy has been estimated at $106 to $238 billion per year (Vernon, 2007). The economic, social, and individual effects of low health literacy have implications for a related issue, numeracy.

Numeracy and Health Numeracy

The term "numeracy" was coined as the "mirror image of literacy" in the mid-twentieth century (Ministry of Education, 1959). Some definitions of numeracy in adult mathematics education literature continue to view it as subsumed within literacy, while others see it as a separate content area and focus on its distinction from "mathematics," or its application to a variety of life contexts (American Institute for Research, 2006). A more comprehensive definition of numeracy is “the ability to access, use, interpret, and communicate mathematical information and ideas, to engage in and manage mathematical demands of a range of situations in adult life" (Organisation for Economic Cooperation and Development, 2012).

As the significance of health literacy became better understood, the health literature also envisioned health numeracy first as a subset of health literacy (Institute of Medicine, 2004). Golbeck and colleagues introduced the concept of health numeracy as a separate entity (Golbeck, Ahlers-Schmidt, Paschal, & Dismuke, 2005). Subsequent literature has continued to treat health numeracy as an independent construct from health literacy (N. D. Berkman, Sheridan, S.L., Donahue, K.E., Halpern, D.J., Viera, A., Crotty, K., Holland,A., Brasure, M., Lohr, K.N., Harden, E., Tant, E., Wallace, I., Viswanathan, M., 2011). This classification is bolstered by evidence that health numeracy is independent from health literacy as a factor in health outcomes (R. L. Rothman, Montori, V. M., Cherrington, A., Pignone, M.P., 2008).

Definitions of health numeracy.

The literature on the application of numerical skills to health often uses the term "numeracy" to refer to one or two specific mathematics tasks related to particular health situations. For example, authors have limited their concept of health numeracy to the understanding of probability in risk assessment (Aggarwal, Speckman, Paasche-Orlow, Roloff, & Battaglia, 2007; Lipkus, Samsa, & Rimer, 2001), or the use of percentages in asthma management (A. J. Apter, Cheng, J., Small, D., Bennett, I.M., Albert, X., Fein, D.G., George, M., Van Horne, S. , 2006). But numeracy, and health numeracy, are broader concepts in both mathematics and life-skills applications. Several authors have acknowledged the broader picture of numeracy (R. L. Rothman, Montori, V. M., Cherrington, A., Pignone, M.P., 2008), (Marilyn M. Schapira et al., 2012), (Ancker & Kaufman, 2007), (Montori & Rothman, 2005), but none has embraced the entire scope of numeracy in a health context. Golbeck provides the most comprehensive definition of health numeracy: "the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions" (Golbeck et al., 2005).

A numeracy framework.

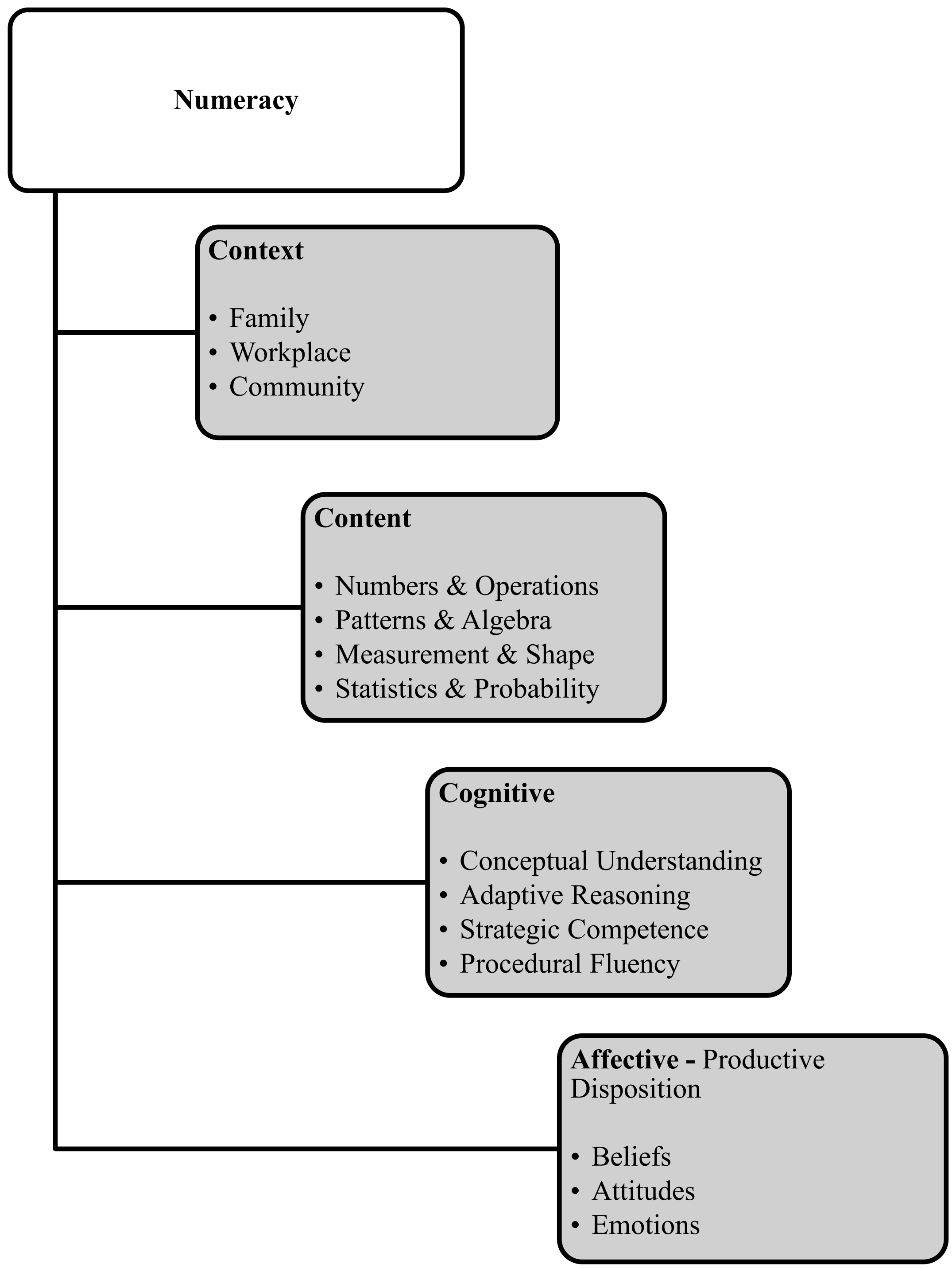
Beyond a comprehensive view of numeracy, a framework is needed to describe the relationships among the components. Researchers have designed frameworks for health numeracy based on theoretical and qualitative interpretations of the use of numbers in health decisions. Golbeck and colleagues proposed four functional categories: Basic, Computational, Analytical, and Statistical (Golbeck et al., 2005). Nutbeam's health literacy skill levels - functional, interactive, and critical - also apply to health numeracy (Nutbeam, 2000). Apter proposed a conceptual model for communication of numerical information using a matrix of numeracy elements and mastery levels required to describe, interpret, or make a decision using numbers (A. Apter et al., 2008). She used it as a tool for planning numeracy communication that would enhance patient autonomy and shared decision-making.

However, these models omit an important group of factors that impact the use of health numeracy. Personal, emotional and attitudinal aspects of engaging in health numeracy activities can make or break a person's entry into the health numeracy process. Therefore this study used a numeracy framework from the adult learning literature that incorporates all these factors. Published by the National Center for the Study of Adult Learning and Literacy, it integrates frameworks from adult numeracy and mathematics in the U.S. and United Kingdom with K-12 and community college frameworks (Ginsburg, 2006). The fundamental elements inherent to proficient adult numeracy are described. Figure 1 shows the components and subcomponents of numeracy in this framework.

Context is the property that differentiates numeracy from mathematics. It connects the use of numbers to a purpose or use via a math-related task. Common contexts are the family, workplace, and community. Content is defined as “the mathematical knowledge that is necessary for the tasks confronted” (Ginsburg, 2006). In this model, mathematical tasks are grouped into four categories of Numbers and Operations, Patterns and Algebra, Measurement and Shape, and Statistics and Probability. A similar but more detailed grouping of mathematics skills is contained in the Common Core State Standards (Appendix A) adopted by most U.S. states and territories (Common Core State Standards Initiative, 2012), which may be more familiar to U.S. residents.

Figure 1. Numeracy Framework: Components and Subcomponents of Numeracy

Adapted from Ginsburg (Ginsburg, 2006)



Cognitive.

Ginsburg groups cognitive and affective numeracy together as both are required to enable an individual to solve problems. They are the link between numeracy and behavior. We will examine the cognitive component briefly, and then the affective in more detail.

The cognitive component of numeracy refers to the application of skills to solve problems (Ginsburg, 2006). The term "functional numeracy" has also been used (Kerr, 2010). These processes link content and context, to enable an individual to solve problems. They include four subcomponents that require further explanation. Conceptual understanding refers to the integrated, functional grasp of mathematical ideas. Adaptive reasoning is the capacity to think about relationships among concepts in a logical way. Strategic competence is needed to formulate, represent, and solve mathematical problems. Finally, procedural fluency is the ability to perform calculations correctly using problem-solving strategies and technological aids (Ginsburg, 2006).

Affective.

Mathematics affect is a complex construct, and includes attitude, interest, locus of control and beliefs (Chamberlin, 2010). Ginsburg described it as the elements that impact a person's ability and willingness to engage in activities that involve numbers, and to persist with those activities (Ginsburg, 2006). This "productive disposition" determines whether the entire process of numeracy activity is implemented, as the individual must be emotionally ready to undertake the task, and to persevere despite confusion, frustration, or ambiguity. The field of mathematics education has explored these issues as related to classroom learning and testing (E. A. Maloney, Ansari, & Fugelsang, 2011; Wu, Barth, Amin, Malcarne, & Menon, 2012), as well as the use of math in daily life. Affective factors play a significant role in activities requiring mathematics reasoning (Erin A. Maloney & Beilock, 2012). Subcomponents of the affective domain are beliefs, attitudes, and emotions, and they develop not solely from schooling, but from life experiences, cultural influences, and perceptions (Ginsburg, 2006).

Beliefs are a set of ideas in which expectations are grounded. New experiences are understood through the lens of beliefs (Ginsburg, 2006). Over time, people develop mathematics-related beliefs about their ability to learn math, the usefulness of mathematics in their lives, and their confidence in attempting math-related problems. As such, they include self-efficacy, the belief in one's capability to produce a given attainment (Bandura, 1977). Self-perceptions of capabilities influence behaviors, including what actions to pursue and how long to engage in them, regardless of whether the assessment of personal efficacy is accurate. People undertake activities they believe they can manage, and avoid those they perceive to exceed their abilities (Bandura, 1982).

Attitudes are feelings and preferences about mathematics, and they vary in direction and intensity. Negative attitudes may be expressed as a dislike of working with numbers or discomfort in asking for help with a problem (Ginsburg, 2006). Positive attitudes are apparent when math is a source of entertainment or personal challenge. Mathematics attitudes impact whether tasks are viewed as a challenge or a nuisance (Fennema, 1976). The amount of energy invested in the task may vary accordingly.

Emotions in response to math can be powerful barriers to completion of tasks involving numbers (McLeod, 1994). Math anxiety is a well-known response. By definition it involves “feelings of tension and anxiety that interfere with the manipulation of numbers and the solving of mathematical problems in a wide variety of ordinary life and academic settings” (Richardson, 1972). Mathematics educators recognize the negative effect of math anxiety on working memory (Ashcraft, 2009; E. A. Maloney et al., 2011), and even basic skills such as counting (E. A. Maloney, Risko, E.F., Ansari, D., Fugelsang, J., 2010). It remains after schooling is completed, and it may be independent of actual mathematics abilities (Eccles, 1986). Individuals with math anxiety avoid situations that use math, and perform poorly on mathematical tasks (Bai, 2008). Visceral threat detection pathways and pain networks in the brain are activated when high math-anxiety individuals anticipate a math-related task (Lyons & Beilock, 2012), producing a physical deterrent to engaging in mathematics activities.

Ginsburg's framework provides a very comprehensive view of numeracy, not only by including the entire range of mathematical content, but especially by giving similar weight to the cognitive and affective components. When the context of numeracy is personal health, an individual's complex and unique relationship with numbers comes into play. Now we look to an area of health in which numbers are a necessary interface between people and health issues. Nutrition is a prominent public health concern, and numbers are central to understanding and communicating information about this topic. We will examine numeracy in the context of nutrition, and then describe a particular population that is the focus of this study.

Numeracy and Nutrition

Even before the birth of nutrition science, food was tied to numbers. Food was measured in the field, the marketplace, and the kitchen. The first USDA food guide for nutritional health in 1916 specified five food groups (Welsh, 1993). The identification of essential nutrients and development of chemical analysis techniques enabled publication of data on the nutrient composition of food, which now appears in a simplified form on food labels. With developments in quantitative understanding of nutrition and health, numerical information about food and nutrition has become more accessible to the public, and expectations for use of that data have become more complex. Many guidelines for healthy eating require multiple step calculations, such as determining "30% of calories from fat" (American Heart Association, 2010). Interpretation of food labels also requires competencies beyond the four basic mathematics functions. Both low literacy (Jay, 2009) and low numeracy (R. L. Rothman et al., 2006) have been associated with poor understanding of food labels. Numbers are an inescapable part of the language of food and nutrition.

Special diets.

When diet is a key preventative strategy or treatment for a chronic medical condition, numeracy expectations may become even more complex. Nutritional intake goals are narrower and food choices may be more limited. The diet plan may set a daily goal or limit for one or more components, with the expectation that intake be tallied throughout the day. In addition, foresight and planning are needed to assure that the day's intake reaches but does not overshoot the goal. Diet management of these chronic conditions also requires measurement, estimation, and conversion of units of measure. When a health condition varies with energy expenditure or medication in addition to food intake, numerical tasks are even more critical to outcomes.

Diet modifications in childhood.

Pediatric conditions add another layer of complexity to the use of numeracy in health, as the amount of food requires finer tuning with smaller body size, and nutrient requirements are dynamic due to growth needs. Parents must be competent in many aspects of numeracy to perform the everyday task of feeding a child with special dietary needs. The process involves changes in food planning, procurement, preparation, scheduling, expenses, and mealtime dynamics (Taylor, 1993). Diet modification for children is challenging: of all recommended medical treatments for chronic pediatric conditions, diet has the lowest rate of adherence (Mackner, McGrath, & Stark, 2001). In a review of the literature on this topic, the diets with the lowest rates of adherence (between 1 and 56%) were those for cystic fibrosis, Type 1 diabetes, phenylketonuria and chronic renal disease (Mackner et al., 2001). These researchers have called for further study of factors related to dietary adherence, given the importance of diet in many chronic pediatric conditions.

Two Pediatric Conditions

This investigation centered on two of these pediatric conditions, as they provide unique opportunities to study relationships between numeracy and outcome. Type 1 diabetes

(T1D), and phenylketonuria (PKU) are both chronic metabolic conditions requiring extensive parent education on diet management (Al Sayah, Majumdar, Williams, Robertson, & Johnson, 2013). In each disorder, a blood test gives a reliable biomarker of adherence to diet. Neither disorder is a consequence or comorbidity of other health conditions that are associated with low numeracy skills, such as obesity which has its own relationship with numeracy (M.M. Huizinga, Beech, Cavanaugh, Elasy, & Rothman, 2008; M. M. Huizinga, S. Pont, et al., 2008). While most research on diet and numeracy has been in patients with type 2 diabetes, the numeracy component of care in T1D is more complex (Cavanaugh et al., 2008). In the next section, these two conditions are described and their current treatment strategies are explained.

Phenylketonuria.

Phenylketonuria is an inherited disorder of protein metabolism. Inheritance is autosomal-recessive, meaning each parent is a carrier of the trait but does not have the disorder. Family history is typically negative for PKU (Screening Technology and Research in Genetics Project, 2013). Since the late 1960's, newborn screening in the U.S. and other developed countries has identified PKU in the first week of life. Incidence is 1 in 10,000 among Caucasians and 1 in 200,000 among African Americans. In the U.S. overall, incidence is 1 in 15,000 live births. PKU is more common in Ireland, Poland, and Turkey (Vockley et al., 2014) due to genetic differences in the populations of those countries.

The building blocks of protein are amino acids, some of which are essential, as humans can't manufacture them from other compounds. Phenylalanine is one of the essential amino acids. A liver enzyme, phenylalanine hydroxylase, breaks down extra phenylalanine beyond the body's needs. PKU results from a deficiency of this enzyme (National Institutes of Health, 2000). With insufficient enzyme activity, high blood levels of phenylalanine in untreated PKU cause severe mental retardation (Vockley et al., 2014). Primary treatment for this disorder is a diet that carefully balances protein needs with strict control of phenylalanine in the diet. Consequences of poor adherence to the diet are neurological damage, progressive loss of IQ points in children, and neuropsychiatric issues at all ages (Wrona, 1979). Societal costs of inadequate PKU treatment include special education services for children, and the loss of productivity due to cognitive impairment and/or mental health issues in adulthood (U.S. Department of Health & Human Services, 2011b). Diet treatment for PKU is life-long (National Institutes of Health, 2000).

The diet for PKU requires strict control of the amount of phenylalanine in the diet to prevent high blood levels, yet to meet essential needs for the nutrient (Singh et al., 2014). High protein foods such as meat, eggs, dairy foods, and legumes are eliminated, while grain products and starchy vegetables are quite restricted. The diet is primarily fruits, vegetables, and specially modified foods such as low protein bread and pasta (Ievers-Landis, 2005). To meet protein needs without additional phenylalanine, individuals must consume a medical protein product, usually as a beverage, several times a day (National PKU Alliance, 2013).

The degree of enzyme deficiency in PKU varies with the individual (Vockley et al., 2014). By monitoring blood levels and dietary intake, the medical team can estimate an individual's tolerance, and identify the optimal daily intake of phenylalanine and medical protein (Singh et al., 2014). "Classic" PKU traditionally describes individuals with little enzyme activity who require a strict diet, while the term "hyperphenylalanemia" indicates greater enzyme activity allowing for a relatively liberal protein restriction. Families are trained to keep a diet record of the child's intake for several days and report it to the clinic. Blood levels of phenylalanine are monitored weekly to monthly, depending on clinic protocol, age of patient, and clinical factors (Freehauf, Van Hove, Gao, Bernstein, & Thomas, 2013). In most U.S. programs, parents take a blood sample from the child's finger, place it on filter paper, and mail it to a laboratory (National PKU Alliance, 2013). Blood levels should be between 2.0 and 6.0 mg/dl in all age groups (Vockley et al., 2014). Nutritional needs change with growth from infancy through adolescence, requiring changes in the dietary prescription (Singh et al., 2014).

Phenylalanine in the diet can be tracked by several methods. Counting phenylalanine in milligrams is the most precise. Some clinics use an exchange system (1 exchange = 15 mg). Depending on a child's phenylalanine tolerance, some families may count protein in grams (Singh et al., 2014). U.S. food labels round protein content to the nearest gram, which is not precise enough for tracking intake. An extensive listing of the protein and phenylalanine of over 6,000 foods is available in print or electronic format (Schuett, 2010). The numeracy skills required for PKU are outlined in Appendix B, mapped to the Common Core State Standards (Common Core State Standards Initiative, 2012).

A medication for the treatment of PKU, sapropterin, received FDA approval in 2007 marketed under the name Kuvan (BioMarin Pharmaceutical, Novato, CA). It enhances the activity of the enzyme phenylalanine hydroxylase in some individuals with PKU, allowing a more liberal diet while keeping blood levels in the goal range. Individuals enroll in a trial period to determine responsiveness to the drug, during which frequent submission of blood levels and food records is usually required. Individuals with more baseline enzyme activity are most likely to respond to sapropterin.

Type 1 Diabetes.

Type 1 diabetes is one of the most common chronic childhood diseases, with a prevalence of one in 400 to 600 in the United States (Kelo, Martikainen, & Eriksson, 2011). Similar to type 2 diabetes, the incidence of T1D has been increasing in North America since the mid-1950's, and children are being diagnosed at a younger age. However, T1D is an autoimmune disease in which the insulin-producing cells of the pancreas are destroyed, leading to insulin deficiency. In type 2 diabetes, reduced sensitivity to insulin is the major factor. Type 2 diabetes strongly tied to obesity, while children with type 1 diabetes are not typically overweight (International Diabetes Federation, 2007).

T1D is not inherited in an identified pattern, but evidence suggests that environmental factors affect those with a genetic predisposition (International Diabetes Federation, 2007). Only 2-4% of children with T1D have a parent with diabetes (Craig, Hattersley,

& Donaghue, 2009). While 94% of U.S. children with type 2 diabetes belong to minority communities, the highest rates of type 1 diabetes are in non-Hispanic white youth. (International Diabetes Federation, 2007).

Type 1 diabetes is a serious threat to health. Children usually present with weight loss, excessive thirst and urination, and lethargy, and may require acute care to treat or prevent ketoacidosis. The goal of type 1 diabetes management is to maintain blood glucose levels to as near normal as possible (Silverstein et al., 2005). Complications can only be prevented or minimized by achieving good control. High blood sugar can cause diabetic coma, neurological damage, blindness and kidney failure. At the other extreme, low blood sugar places the child in immediate danger of seizures and death(International Diabetes Federation, 2007). Yearly costs of type 1 diabetes in the U.S. are estimated at $14.4 billion, including medical costs and lost income (Tao, 2010).

Intensive education for the parents of a child with T1D begins shortly after diagnosis. Tasks include monitoring of blood glucose levels using a glucose meter at home several times a day. Frequency of monitoring is closely related to glucose control. Patterns in blood levels before or after meals, overnight, or surrounding physical activity inform adjustments in dosing of insulin. A memory chip in most blood glucose meters records frequency of monitoring and results, enabling observation of trends by parents or clinicians. Daytime blood glucose goals are 100-180 mg/dl for children under 6 years, and 90-180 for 6 to 12 year olds. Parents learn to administer insulin, and to adjust the doses daily according to diet and physical activity. Some children are able to use an insulin pump instead of injections. (Silverstein et al., 2005). Children are taught self-care as developmentally appropriate.

Median glycosylated hemoglobin ($A1_C$) reflects average glucose levels over several months, and predicts diabetes complications. Blood levels are usually measured every 3 months, or as clinically indicated; an $A1_C$ value at or below 7.5 is recommended for all ages in pediatrics (Chiang, Kirkman, Laffel, & Peters, 2014).

The primary goal of dietary treatment for T1D is to maintain blood glucose levels in the desired range (American Diabetes Association, 2003). The focus of the diet is the carbohydrate content of meals and snacks. The type of carbohydrate is less important than the amount and timing throughout the day, and adjustment of insulin dose according to carbohydrate intake (Silverstein et al., 2005). Dietary fat and cholesterol intakes are also modified to prevent cardiovascular complications of diabetes. Other nutrient requirements are similar to children without diabetes (American Diabetes Association, 2003). Using the Common Core State Standards (Common Core State Standards Initiative, 2012), the numeracy skills required for T1D are described in Appendix C.

Complex diets and numeracy.

PKU and T1D are both serious chronic pediatric conditions in which nutritional intake is the primary treatment and a key factor in outcome. Management of both conditions requires numeracy tasks throughout the day. Diet management is complex and involves planning and recording a child's intake of nutrients in very small quantities: grams or milligrams. That diet adherence often falters is not surprising. Parents who struggle with the expected management tasks may become less engaged in care, and complete fewer blood samples or diet records. Difficulty with diet management has been documented in both PKU (MacDonald, 2000; MacDonald, Gokmen-Ozel, van Rijn, & Burgard, 2010; Walter, 2002) and T1D (Bowen et al., 2013; Cavanaugh et al., 2008; Hassan & Heptulla, 2010). Extensive learning resources for families and teaching programs for clinicians have been created for both PKU (Cristine M. Trahms Program for Phenylketonuria, 2008; National PKU Alliance, 2013), and T1D (International Diabetes Federation, 2014; University of California San Francisco, 2013), including computer applications (Cambrooke Foods, 2010; Kerr, 2010). However, none of these aids circumvents the use of numbers entirely.

This study examined a more fundamental question about the underlying factors that predispose parents to success or difficulty in meeting treatment goals. What can the extreme diets of PKU and T1D teach us about how numeracy affects a parent's ability to manage a child's diet? Researchers have called for further study of the underlying factors that impact management of complex diets (MacDonald et al., 2010; Mackner et al., 2001; U.S. Department of Health & Human Services, 2000), and clarification of the pathway between numeracy and health outcome (Bekhof et al., 2003; N. D. Berkman, Sheridan, S.L., Donahue, K.E., Halpern, D.J., Viera, A., Crotty, K., Holland,A., Brasure, M., Lohr, K.N., Harden, E., Tant, E., Wallace, I., Viswanathan, M., 2011; Paasche-Orlow & Wolf, 2007). This study sought to shed light on these concerns.

The Problem

The purpose of this study was to evaluate the relationship between parental numeracy and health outcomes of their children who require complex diets. To what degree is parental numeracy related to achievement of treatment goals? Does cognitive numeracy act as a direct barrier to diet management? Or does numeracy foster indirect barriers to diet adherence via affective pathways, including via self-efficacy? This study assessed the relationship between parental numeracy and child diet management, focusing on two health conditions that require complex diets.

Hypotheses.

1. The hypothesis was that children of parents with lower cognitive and affective numeracy would have poorer control of their chronic condition.
2. It was predicted that self-efficacy would mediate the relationship between numeracy and both engagement in disease management and indicators of health outcomes.

Delimitations.

Inclusion criteria for this study was parents and other primary caretakers of children ages 12 months to 12.9 years who had been diagnosed with PKU or T1D for at least one year. Parents of children age 13 and up were excluded as at this age children are expected to take over a substantial degree of self-care of their disorder, including blood monitoring and diet management (Kelo et al., 2011; Silverstein et al., 2005; Trahms, 2008).

Participants were excluded if the child had been diagnosed with hyperphenylalanemia, the mild form of PKU, as the diet for that disorder is more liberal than classic PKU. Likewise, the current use of the medication Kuvan disqualified participation. Certain test instruments are not available in foreign languages; therefore participants must be literate in English.

Participants were primarily recruited at the outpatient clinic where they received care for PKU or T1D. Due to the low prevalence of PKU, additional participants were sought at community events for families of individuals with PKU in order to enroll an adequate sample.

Limitations.

This study had several limitations. Selection was not random, and recruitment strategies may have favored parents who were more literate or more self-confident, who had more outgoing personalities, and/or who had children in better control and who may have been more likely to submit frequent blood levels. Participants may not have been truthful about their mathematics attitudes or self-efficacy. By omitting children with PKU who are on the medicine Kuvan, we may have eliminated children with greater tolerance for phenylalanine.

Blood levels of children with either PKU or T1D may be affected by factors other than dietary control alone. In PKU, metabolic changes during infection, inflammation, and injury cause elevated blood levels of phenylalanine (Singh et al., 2014). In T1D, blood glucose levels also rise during illness, and additionally may be affected by stress, fatigue, and other factors (Chiang et al., 2014). Data in this study was not adjusted for these influences, as the information was not available from either PKU or T1D clinic data.

In pathway analysis, we assumed that numeracy, as measured by the mathematics test and math attitude instrument, enables parents to do the required mathematics tasks for disease management. But other unmeasured factors may have been involved, such as motivation to comply with the diet, parenting skills that influence ability to enforce a food regimen, or availability of prescribed foods in the home. In addition, the mathematics test measured numeracy skills without use of a calculator, although parents may use one in the actual process of daily diet calculations.

Assumptions.

In this study, the characteristics of parents were examined in relation to their children's health outcomes. This study concerned adult health numeracy, and utilized scales designed and validated for adults. While children ideally begin to learn about their health needs from an early age, and participate in self care as developmentally appropriate, the health numeracy tasks used in the care of children in this study will be the responsibility of their parents.

Engagement was measured by the number of blood samples measured compared to clinic recommendations. This measure served as a proxy for diet adherence, under the assumption that submitting blood samples indicated they were also engaged in trying to manage the diet in accordance with clinic recommendations.

The research also assumed that parents had the vision and reading skills necessary for completion of the instruments. It was assumed that blood levels hadn't been influenced by other factors such as illness or irregularities in blood collection or analysis techniques.

Definitions.

Phenylketonuria (PKU) is an inherited disorder of protein metabolism. It is also referred to as phenylalanine hydroxylase deficiency in the literature. **Hyperphenylalanemia** is a mild form of this condition. **Type 1 diabetes** (T1D) has also been called "juvenile onset diabetes" or "insulin-dependent diabetes." For the purpose of this study, "**parent**" referred to a primary caretaker of the child with T1D or PKU. This may have included grandparents, guardians, or foster parents who assumed day-to-day care of the child.

Health literacy was defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Ratzan, 2000). **Numeracy** is “the ability to access, use, interpret, and communicate mathematical information and ideas, to engage in and manage mathematical demands of a range of situations in adult life” (Organisation for Economic Cooperation and Development, 2012). **Health numeracy** was defined as “the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions" (Golbeck et al., 2005).

Cognitive numeracy refers to the application of skills to solve problems, while affective numeracy is made up of the elements that impact a person's ability and willingness to engage in activities that involve numbers, and to persist with those activities (Ginsburg, 2006).

Self-efficacy was defined as the belief in one's capability to produce a given attainment (Bandura, 1977). The definition of **math anxiety** used in this paper was "feelings of tension and anxiety that interfere with the manipulation of numbers and the solving of mathematical problems in a wide variety of ordinary life and academic settings" (Richardson, 1972). **Engagement** referred to the parent's level of participation in the monitoring of the child's PKU or T1D, and was evaluated by the number of blood levels taken as a proportion of the number expected by the clinic.

Summary

This study used the complex diets required for PKU and T1D to look at relationships between numeracy and health outcomes. The following section examines the literature on health literacy and numeracy relative to health outcomes, dissects the concept of numeracy into its component parts, identifies the mathematical expectation of parents who have a child with specific chronic disorders treated by a complex diet, and considers a theoretical model to guide this study. Numeracy may be a direct and/or indirect factor in the ability of parents to be successful in caring for their child with a chronic condition on a specialized diet, and the goal of this study was to identify salient factors on the pathway between numeracy and outcomes.

CHAPTER II

REVIEW OF LITERATURE

The purpose of this study was to investigate the numeracy-related factors that impact health outcomes in children on complex diets. The literature that informs this research comes from the diverse fields of medicine and public health, mathematics, psychology, education, nutrition and dietetics, and communication. Health literacy research blossomed in the first ten years of this century, and health numeracy studies began to surface in the middle of that decade. Although outcome studies have been relatively recent, the literature provides many studies regarding literacy and numeracy as related to outcomes in several chronic health conditions, and prior studies provide necessary background.

As background for this study, the literature was searched to locate research findings specific to health literacy and numeracy as related to health outcomes, and to capture existing knowledge on factors that may explain this relationship. Relevant sources were those that examined numeracy from an applied perspective, or articles applying numeracy or literacy to health. Search terms used were "health literacy," "numeracy," "health numeracy," "self-efficacy," in combination with "diabetes," "Type 1 diabetes," "glycemic control," "phenylketonuria," "PKU," "parents," and "health." The latter terms were also searched in combination with "mathematics," and "math anxiety" to find literature that explored the cognitive and affective components of numeracy.

An additional search combined selected terms with "assessment," questionnaire," or "measure." The databases PubMed, Medline-Ovid, EBSCO Academic Search Premiere, and CIHAHL were searched with no restrictions on date of publication.

The literature describes evidence of a relationship between literacy and health outcomes, but the relationship between numeracy and health is less clear. This review addresses literacy briefly, and numeracy in greater depth. The literature does not adequately explain the route by which numeracy impacts health, and provides little evidence on its role in parental management of childhood health conditions. Numeracy in PKU has not been examined at all. The impact of numeracy on health outcomes is not fully explained by the current literature, and this study intended to add to the understanding of that relationship.

Health Literacy

Health literacy and health outcomes.

The many studies addressing the association between health literacy and health outcomes have been summarized in comprehensive reviews of the topic (N. D. Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; D. A. Dewalt, Berkman, Sheridan, Lohr, & Pignone, 2004). They conclude that low health literacy can have a substantial role in health outcomes. Many government departments that examine national public health issues also recognize the significance of this relationship. The Institute of Medicine, for example, cites cumulative and consistent research findings that support a connection between limited health literacy and health outcomes (Institute of Medicine, 2004). This relationship is the basis for objectives, recommendations, and resources concerning health communication offered by Healthy People 2020 (U.S. Department of Health & Human Services, 2013), the Centers for Disease Control and Prevention (2013), and the Healthcare Resources and Services Administration (2012). Key medical organizations, including the Joint Commission, American Medical Association, and the Agency for Healthcare Research and Quality, also regard health literacy as a fundamental issue in health outcomes (Yin et al., 2012).

On the other hand, the role of health literacy in dietary outcomes and nutrition behaviors has not been thoroughly researched. A recent review of the literature on health literacy and nutrition (Carbone & Zoellner, 2012) found 33 relevant studies, but most were evaluations of the readability of nutrition materials in print or on websites. A few descriptive studies have addressed nutrition-related skills such as estimation of portion sizes (M. M. Huizinga et al., 2009) and comprehension of nutrition labels (R. L. Rothman et al., 2006). However insufficient research has been conducted on the relationship between health literacy, including numeracy, and diet adherence or outcomes.

The pathway between health literacy and outcomes.

Health literacy is significant: some have considered it to be a stronger predictor of health than age, race, income, employment status or education(Al Sayah, Majumdar, et al., 2013). The causal pathway between health literacy and outcomes has not been fully established (Institute of Medicine, 2004). Berkman et al identified health-related knowledge, self-efficacy, and beliefs as explanatory factors that mediate the relationship, and called for research on the pathway using control variables on a causal pathway (N. D. Berkman, Sheridan, S.L., Donahue, K.E., Halpern, D.J., Viera, A., Crotty, K., Holland,A., Brasure, M., Lohr, K.N., Harden, E., Tant, E., Wallace, I., Viswanathan, M., 2011). Some researchers consider health literacy to be a key explanation for the effects of demographic factors or social determinants on health. Yin concluded that health literacy may act as a mediator of racial/ethnic health disparities (Yin et al., 2009; Yin et al., 2012), and Abrams identifies health literacy as a possible mediator of adult health disparities in general (Abrams et al., 2009). Others consider health literacy as a social determinant of health in its own right (Baur, 2010). Paasche-Orlow & Wolf identify three points along the pathway linking health literacy to health outcomes: access to health care, patient-provider relationship, and self-care practices (Paasche-Orlow & Wolf, 2007).

Research is needed to understand this relationship, especially as it applies to children, who have a unique place in the national health literacy agenda (Abrams et al., 2009). One in four U.S. parents has limited literacy skills (Yin et al., 2009). A key recommendation to improve health inequities of children is meeting the health literacy needs of their parents (Sanders, Shaw, Guez, Baur, & Rudd, 2009), as children of low literacy parents have worse health outcomes than those with more literate parents (Sanders, Federico, Klass, Abrams, & Dreyer, 2009). A review of the literature on health literacy and child health outcomes concludes that the relationship is independent of the effects of literacy on the use of health services, and calls for further research on both causal and non-causal pathways between parent literacy and health outcomes (D. H. DeWalt, A., 2009).

Health numeracy is viewed as a subcomponent of health literacy in some publications, and as an independent factor in others. Therefore, research on health numeracy is found both within health literacy studies, and in numeracy-specific articles. Subjective measures of numeracy and health literacy have indicated that they are related but unique skills (C. D. McNaughton, Rothman, R., Marcovitz, D.E., Storrow, A.B., 2011). In studies that have assessed both health literacy and numeracy in relation to the same health outcomes, numeracy has been more highly correlated with outcomes than health literacy (Marden et al., 2012; R. L. Rothman et al., 2006).

Health Numeracy

Health numeracy and social characteristics.

In the U.S., poor numeracy skills are more common than poor literacy. In a recent international assessment of adult cognitive and workplace skills, by the National Center for Health Statistics, 18% of the U.S. sample had low literacy (Level 1 or below), including 4% with below basic skills. In comparison, low numeracy was present in 30% of the sample, with 10% below basic skills (Goodman, 2013). This data also captured differences in numeracy by demographic factors. Females were more likely to have low numeracy skills than males, with 33% of women having Level 1 scores or below, while 27% of males were in this category. Numeracy skills vary with race/ethnicity. Low numeracy was identified in 59% of blacks, 56% of Hispanics, and 19% of whites. A study of health literacy and numeracy skills among Spanish-speaking parents of young children, in which all assessments were conducted in Spanish, found a profound discrepancy between health literacy (77% adequate) and numeracy abilities (0.6% adequate) of participants (Yin et al., 2012).

Many social determinants of health are related to numeracy skills. Individuals with low socioeconomic status and educational achievement have more difficulty with numeracy tasks (Montori & Rothman, 2005). As expected, a higher percentage of adults who are unemployed have low numeracy skills than those who have jobs (42% versus 25%) (Goodman, 2013). U.S. adults performing at low numeracy levels are far more likely to receive social assistance than those with better numeracy skills (Ginsburg, 2006). Education increases the likelihood of excellent numeracy, but does not guarantee it. While 63% of individuals with less than a high school education had low numeracy, 35% of high school graduates and 16% of those with an associate's degree were also in that category (Goodman, 2013). Even among holders of a bachelor's degree, 9% scored at Level 1 or below. Low numeracy in the U.S. is thus widespread and clustered in disadvantaged population groups. Is the poor status of numeracy in the U.S. reflected in health outcomes?

Numeracy and health outcomes.

Adult numeracy skills vary with self-reported health status. Of those reporting poor or fair health status, 51% have low level numeracy skills, while 21% of adults reporting excellent or very good health have low skills (Goodman, 2013). Several studies have evaluated the impact of health numeracy on outcomes in chronic health conditions. Berkman and colleagues performed an extensive review of the evidence on the topic, and stated that the literature was inconclusive without a broader evidence base and studies that distinguish between print and numeracy components of health literacy (N. D. Berkman, Sheridan, S.L., Donahue, K.E., Halpern, D.J., Viera, A., Crotty, K., Holland,A., Brasure, M., Lohr, K.N., Harden, E., Tant, E., Wallace, I., Viswanathan, M., 2011). A closer look at this body of literature reveals findings about the factors that affect the pathway between numeracy and health outcomes.

Asthma is a chronic condition that requires daily, involved health decisions about medication dosing and treatment choices that require the use of numbers. Apter et al developed a disease-specific tool based on typical asthma self-care instructions to assess understanding of numerical concepts (A. J. Apter, Cheng, J., Small, D., Bennett, I.M., Albert, X., Fein, D.G., George, M., Van Horne, S. , 2006). They found a significant negative association between numeracy scores and both hospitalization and emergency room visits for asthma. Adjustment for age, sex, income, and education did not change this association. A related study identified the impact of low numeracy skills on asthma-related quality of life. Income and self-efficacy were mediators of this relationship (A. J. Apter et al., 2009). HIV infection also requires numeracy skills for adjusting medication. Numeracy has been identified as a mediator of the relationship between gender and management of HIV medication (Waldrop-Valverde, Osborn, et al., 2010), and between race and medication self-management (Waldrop-Valverde, Jones, Gould, Kumar, & Ownby, 2010; Waldrop-Valverde, Osborn, et al., 2010).

Individuals with heart failure must use numbers to monitor their daily weight and sodium intake, and to titrate medications, as well as undertaking tasks related to comorbidities such as diabetes, kidney disease and chronic lung disease. Among those presenting to emergency departments with acute heart failure, a low score on a subjective self-evaluation of numeracy was associated with a greater likelihood of 30-day recidivism (C. D. McNaughton, Collins, S.P., Kripalani, S., Rothman, R., Self, W.H., Jenkins, C., Miller, K., Arbogast, P., Dittus, R.S., Storrow, A.B., 2013), although health literacy was not. Anticoagulation therapy also requires numeracy skills, with multiple dose changes per day, requiring frequent changes in the strengths or numbers of tablets per day. In a study of numeracy and anticoagulation control, people with lower numeracy had greater variability in the blood levels that indicate good control. Variability is associated with greater risk of bleeding or stroke. Those with low numeracy spent more time with levels above their therapeutic range (Estrada, Martin-Hryniewicz, Peek, Collins, & Byrd, 2004). Errors occurred when patients misunderstood the instructions, or could not perform simple computations. Estrada noted that the self-reported highest level of schooling completed was not a reliable measure of a patient's abilities.

Numeracy and health outcomes in diet-related conditions.

Most research on numeracy and diet management has been studied among individuals with diabetes. A study from the United Kingdom of adults with T1D evaluated the correlations between literacy and numeracy with $HgbA_{1c}$ (Marden et al., 2012). Literacy was not associated with glycemic control but math skills had a significant association. The connection between poor numeracy and poor diabetes outcome was not explained by education and income, however. Although individuals with higher socioeconomic status (SES) were more likely to have lower HbA_{1c}, the relationship between numeracy and glycemic control was independent of SES.

A U.S. study of adults with T1D or -2 used a general numeracy tool as well as the Diabetes Numeracy Test (DNT), a validated instrument with diabetes-specific questions, such as calculating an insulin dose (Cavanaugh et al., 2008). Lower general numeracy was associated with significantly lower DNT scores, and low diabetes numeracy was associated with higher $HgbA_{1C}$ levels. However, general numeracy was not associated with glycemic control. After regression analysis controlling for age, race, income, and other factors, the association between diabetes-related numeracy and glycemic control was modest. The association between low DNT scores and poor control was stronger among individuals with T1D than DM-2. Authors expected this observation, as diabetes care in T1D is more complex. A test of significance was not possible due to the small sample size of T1D.

In a related study, better diabetes-related numeracy predicted glycemic control such that the association between African American race and diabetes outcome became non-significant (C. Y. Osborn, Cavanaugh, Wallston, White, & Rothman, 2009). Authors concluded that diabetes numeracy was a mediator in the relationship between race and glycemic control. In both studies, the distinction between general and diabetes-related numeracy is significant in the interpretation of the results. The diabetes skills test measures comprehension and application of the diabetes education provided by the clinic. Successful acquisition of those skills differs from the individual's general numeracy skills at the time of diagnosis, and may relate to other characteristics such as motivation, attentiveness, and interest in learning.

Few studies evaluate the impact of adult numeracy on the care of children with diabetes. One paper documented a significant positive relationship between mother's literacy (ability to correctly read a list of words) and the glycemic control of her child with T1D, but the parent's numeracy skills were not measured (Ross, Frier, Kelnar, & Deary, 2001). In a study of parents and other caretakers of children with T1D, the lack of basic numeracy skills, as measured by an applied numeracy test, had a detrimental effect on glycemic control (Hassan & Heptulla, 2010). The children of parents with better scores on a math test had significantly lower HbA_{1c} levels. When controlling for confounders, math skills were significantly related to income.

Beyond diabetes, little has been published on numeracy in managing diets. In 2003, the Surgeon General cited health literacy, including numeracy, as one of the largest contributors to overweight and obesity in the U.S. (Carmona, 2003). An association between parental numeracy and childhood obesity has been discussed (M. M. Huizinga, S. Pont, et al., 2008), but surprisingly little research documents this relationship. One study found that literacy skills and BMI were not related, but adults with low numeracy skills (less than the ninth grade level) were significantly more likely to have a higher BMI (M.M. Huizinga et al., 2008). The relationship remained consistent after adjusting for age, sex, race, income, and years of education.

Numeracy in other conditions requiring diet changes that depend on mathematical skills, such as chronic renal disease and uncontrolled seizure disorders, has not been studied. The need exists, however, as poor compliance with special diets has been documented in many chronic conditions including pediatric disorders (Mackner et al., 2001), and the factors impacting adherence are not clear.

In PKU, adherence is difficult and many families are unable to maintain treatment acceptably (MacDonald, 2000), (Fisch, 2000). Compliance with prescribed treatment is usually assessed by comparing blood concentrations of phenylalanine to the goal range (Cotugno et al., 2011; Freehauf et al., 2013). Reviews of PKU compliance document adherence rates near 50% (MacDonald et al., 2010) (Cotugno et al., 2011). In a study of the effect of parental factors on blood phenylalanine levels in children, poor parental educational achievement influenced overall control, but the relationship was not statistically significant (MacDonald et al., 2008). Others have cited the effect of family cohesion, language or cultural barriers between families and health providers, and difficulty in food preparation on poor compliance with dietary treatment of PKU (MacDonald et al., 2010). In a study of behavioral factors, parental belief that the child adhered to the diet, even if blood levels were sometimes high, was significantly related to good metabolic control (Crone, 2005). Numeracy has not been evaluated as a factor in poor adherence to PKU treatment. Considering the findings in diabetes and the similarity of treatment challenges, it is plausible that parental numeracy is a variable in outcomes of children with PKU.

Application of numeracy components to special diets in general, and to PKU and DM1 treatment in particular

What are the numeracy tasks that parents need in order to successfully manage specialized diets? Using the numeracy framework in Figure 1, we reviewed the literature on the use of numbers in complex pediatric diets such as PKU and T1D. The constructs of the framework are discussed in turn below.

Context.

Mathematics is used in the management of pediatric diets in the large context of the family, the particular contexts of parenting and managing child health needs, and very specific contexts of mealtime, food preparation, menu planning, shopping decisions and the like. Numeracy has been studied in several tasks utilized in managing special diets: portion-size estimation (M. M. Huizinga et al., 2009), diet recalls or food frequency questionnaires (Bowen et al., 2013), understanding of food labels (R. L. Rothman et al., 2006) , and use food composition data presented in a table (Visschers & Siegrist, 2010). In all contexts, low numeracy was associated with poor performance of the mathematics-related task. Numeracy in DM1 and PKU includes all of these contexts and others, such as monitoring and recording of health data, and in DM1, medication management. To study the relationship between numeracy and health outcomes in these disorders, we needed to identify the specific mathematics skills, the content component of numeracy, required to complete each task.

Content.

The content of math knowledge used in special pediatric diets varies with the condition and the management goals. Standards of care have been written for PKU (National PKU Alliance, 2013), and for DMI (American Diabetes Association, 2013), and specific mathematical skills are needed for individual tasks. Tables in Appendices B and C list the tasks for PKU and T1D, respectively. The tables classify the mathematical knowledge needed for each task into the categories Numbers and Skills, Measures, Shape, and Space, and Handling Data (Excellence Gateway, 2013). The tables also indicate the corresponding mathematical content standard of the Common Core State Standards listed in Appendix A (Common Core State Standards Initiative, 2012). Most of the skills listed are required in both disorders, although more of the activities for the PKU diet are related to infant formulas due to usual age of diagnosis, and DMI requires distinct skills to calculate medication dosages (M. M. Huizinga, T. A. Elasy, et al., 2008). Neither disorder requires statistics or probability skills. In either disorder, mathematical knowledge is necessary for diet management tasks.

Cognitive.

Diet management involves many of the subcomponents of the cognitive aspect of numeracy: 1) conceptual understanding, to estimate and round food content data, 2) adaptive reasoning, to think logically about adjusting for the portion of a serving that was not consumed, 3) strategic competence, to organize information from a table into a mathematical form such as a column of numbers to be totaled, and 4) procedural fluency, to perform the calculation using either mental math or a calculator. Other components of the cognitive skill set, working memory, attention, and processing speed, are also needed (Wolf et al., 2009). Functional numeracy is needed to decide when to use each mathematics skill (Kerr, 2010). In diet management, these areas impact a parent's ability to solve problems such as substituting one food for another, to plan strategies to achieve an intake goal, and to complete numerical tasks smoothly and efficiently.

Research supports the importance of cognitive skills, as mathematical competence alone does not guarantee success in numeracy applications related to food. In the study of health numeracy and interpretation of nutrition labels, for instance, many individuals with higher education had difficulty with comprehension (R. L. Rothman et al., 2009). In the study of portion-size estimation skills, participants of all educational levels had difficulty, (M. M. Huizinga et al., 2009). Adults with diabetes have difficulty with functional numeracy tasks such as food label interpretation and insulin adjustment based on blood glucose readings (M. M. Huizinga, T. A. Elasy, et al., 2008). Thus cognitive numeracy skills are key in successful outcomes in health conditions requiring special diets.

Affective components

Beliefs, attitudes, and emotions concerning the use of numbers are especially relevant to the application of mathematics in diet-related activities. Since parents must fit numeracy tasks into their daily lives, obstacles to undertaking such tasks are very significant, regardless of numeracy abilities. The literature on these affective components of numeracy is explored below.

Beliefs: Self-Efficacy.

Research on beliefs in health literacy and numeracy has focused on self-efficacy. An extensive review by Berkman et al concluded that self–efficacy is likely to be on the causal pathway between health literacy (including numeracy) and health outcomes (N. D. Berkman, Sheridan, S.L., Donahue, K.E., Halpern, D.J., Viera, A., Crotty, K., Holland,A., Brasure, M., Lohr, K.N., Harden, E., Tant, E., Wallace, I., Viswanathan, M., 2011). Several studies provide evidence of the influence of self-efficacy on clinical outcomes in chronic illness. Low self-efficacy predicts poor adherence to treatment for HIV/AIDS (Barclay et al., 2007). The numerous studies indicating a positive association between self-efficacy and diabetes outcome have been summarized (Mohebi, Azadbakht, Feizi, Sharifirad, & Kargar, 2013). In a study that included dietary behavior, low self-efficacy was related to fewer self-management behaviors including diet (Sarkar, 2006). An analysis of the pathway linking health literacy and numeracy to glycemic control found self-efficacy to be a significant factor. Both health literacy and numeracy were associated with greater diabetes self-efficacy, and self-efficacy predicted better glycemic control. Further analysis showed numeracy was more closely related to self-efficacy than health literacy (C. Y. Osborn, Cavanaugh, Wallston, & Rothman, 2010). A recent study of 49 parents of children with T1D found a positive association between parental self-efficacy and children's glycemic control (Marchante, 2013). These findings emphasize that parents' self-efficacy beliefs regarding numbers are important, and should not be overshadowed by the cognitive aspects of numeracy in the study of numeracy and diet management.

Attitudes Towards Mathematics.

Attitudes towards mathematics have not been studied extensively in the health literature. Wolf (2009) recognized a psychosocial skill set, in addition to a cognitive one, as fundamental to functional health literacy and numeracy. Joram notes in a diabetes-related article that even highly educated individuals may have an aversion to numbers (Joram et al., 2012). In mathematics education research, attitudes towards math have been examined for decades, as the strength and direction of feelings about mathematics impacts motivation to engage in math activities (Fennema, 1976). Applying this insight to parents of children with complex diets, attitudes towards mathematics may impact a parent's decision whether to engage in diet-related numeracy activities, and whether to re-engage after a period of frustration.

Emotions: Math Anxiety

Math anxiety is a well-recognized emotion related to numbers, and Shapira is one of the few authors to mention it as a factor that could interfere with processing of numeracy problems in a health context (M. M. Schapira et al., 2008), (M. Schapira et al., 2011). While math anxiety has rarely been studied in health-related activities, the possibility of it clouding the assessment of numeracy in health applications has been acknowledged (R. L. Rothman, Montori, V. M., Cherrington, A., Pignone, M.P., 2008). This study was based on the premise that it may overshadow the real-life utilization of numeracy as well.

Math anxiety could easily be an obstacle to engaging in numeracy activities for special diets. The functional impact of math anxiety could interfere with accuracy of cognitive tasks. For example, avoidance may result in skipping important steps in calculating an insulin dose, "fudging" diet records, or neglecting to complete and submit the record to the clinic.

In summary, the literature on the components of numeracy explains why numeracy content should be studied as a factor that may impact health outcomes when parents are expected to use math processes to manage special diets. The specific tasks described in Appendices B and C make it clear that successful implementation of the diets for PKU and DM1 depends on the use of numbers in several subcomponents of numeracy content. The literature also exposes an aspect of numeracy– the affective component, including beliefs, attitudes, and emotions - that has not been consistently acknowledged in health numeracy literature, but is likely to be important when mathematical skills are needed for management of health conditions. This study explored the impact of these numeracy components on the pathway linking health behavior and outcomes.

A Model of the Pathway Between Numeracy and Health Outcomes

A theoretical framework of the relationships among factors impacting health behavior and outcomes was the frame of reference for this study. One such model, applied to persons of Mexican-American ethnicity, was developed based on a qualitative study using focus groups (M. Schapira et al., 2011). Reflecting the themes gleaned from interviews, the model showed affective and cognitive responses as two separate components influencing the application of numeracy skills in ten different health contexts, leading to health behaviors and outcomes. This model might apply to this and other studies as it portrays both cognitive and affective responses as mediators of the relationship between health numeracy and outcomes. However, besides being specific to one ethnic group, the model has limited usefulness to other health numeracy applications for two reasons. First, the model reflects a somewhat narrow concept of health numeracy. Of the nine key numeracy questions asked in the focus groups, eight concerned the use of numbers when communicating with a doctor, when evaluating probability and risk, or numbers in interpretation of medical studies. Second, the affective response themes were trust versus skepticism of numerical information, and reassurance versus fear of the medical situations that numbers described. Thus the context of health numeracy in this study, the day-to-day practical application of basic numeracy skills in disease management, differs significantly from the model presented by Shapira et al; and the related affective responses differ as well. Therefore, the Shapira model was unusable for the application of numeracy in this study, in which cognitive numeracy may impact the ability to complete a task correctly, and the affective component of numeracy may determine whether an individual chooses to engage in numeracy activities at all.

A more appropriate theory to explore dietary adherence as a health behavior was the Health Belief Model (Becker, 1974) which identifies factors that impact health decisions in a broad sense. Constructs that predict the likelihood of a health-related action include 1) perceived threat of disease, 2) the balance between barriers and benefits, and 3) self-efficacy (Figure 2). Application of this model to dietary management of children with PKU and T1D aids in understanding compliance with diet modifications. Figure 3 depicts the application of the Health Belief Model to complex diets for children. The perceived threat of disease includes parents' perception of the risk that poor control of the disorder will result in unfavorable health outcomes. The ultimate result is the likelihood of completing the tasks required for diet management. Lack of knowledge about how to implement the diet is one example of a barrier, but others could be the inability to access the required food, a lack of food preparation equipment, or the child's food refusal.

In Figure 4, numeracy was added to the previous model to depict possible pathways of influence, with separate pathways for its two components, cognitive and affective. The effect of cognitive numeracy skills on outcome is via barriers imposed by inability to perform mathematical tasks, and impaired procedural fluency needed to perform calculations efficiently. Misunderstandings of diet instructions and diet planning may occur due to poor cognitive skills. The affective component of numeracy may influence parents' beliefs about their abilities via self-efficacy, while anxiety and other emotions may be a barrier to engaging in numerical tasks. An attitude of embarrassment over poor math abilities could keep a parent from engaging in communication with the healthcare team. The Health Belief Model provided a framework through which to explore the existence and strength of these relationships in an organized research study.

Figure 2. The Health Belief Model (Becker, 1974)

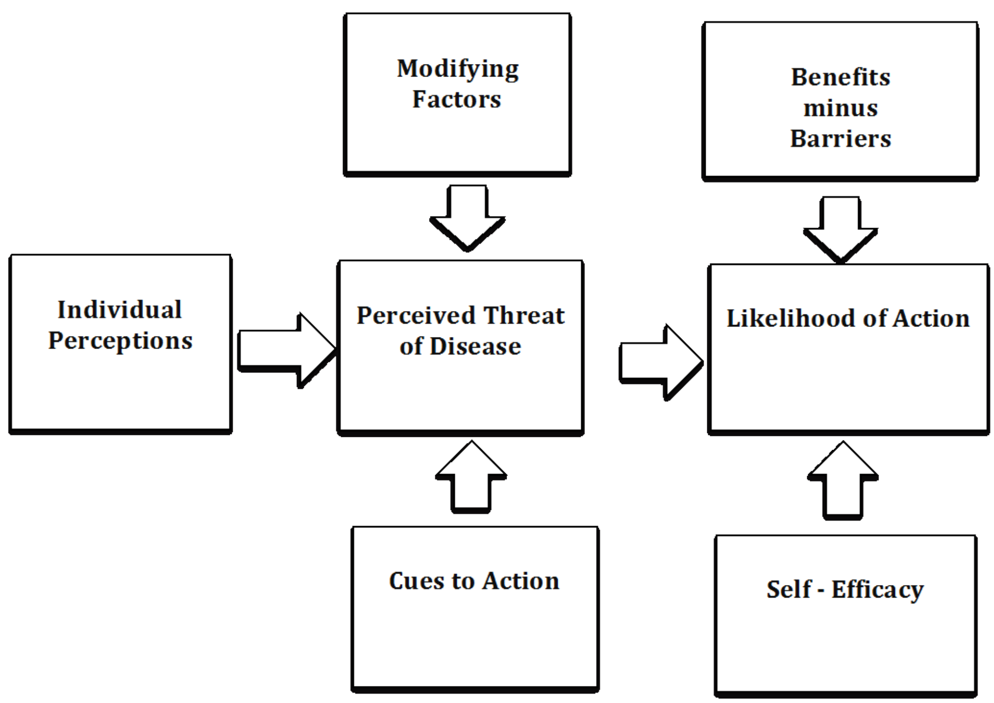
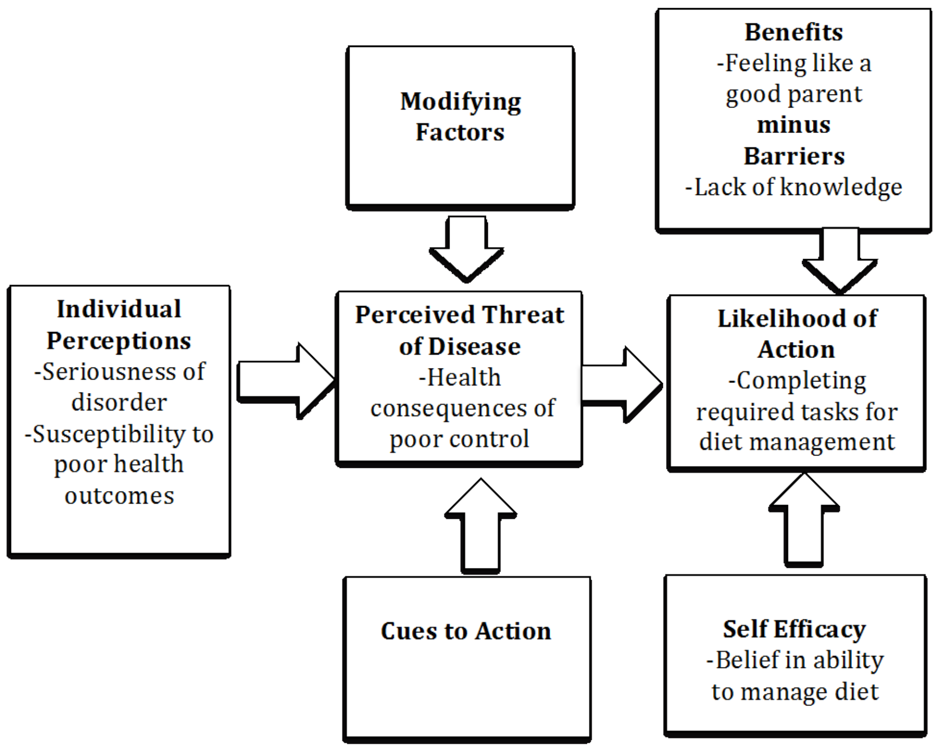
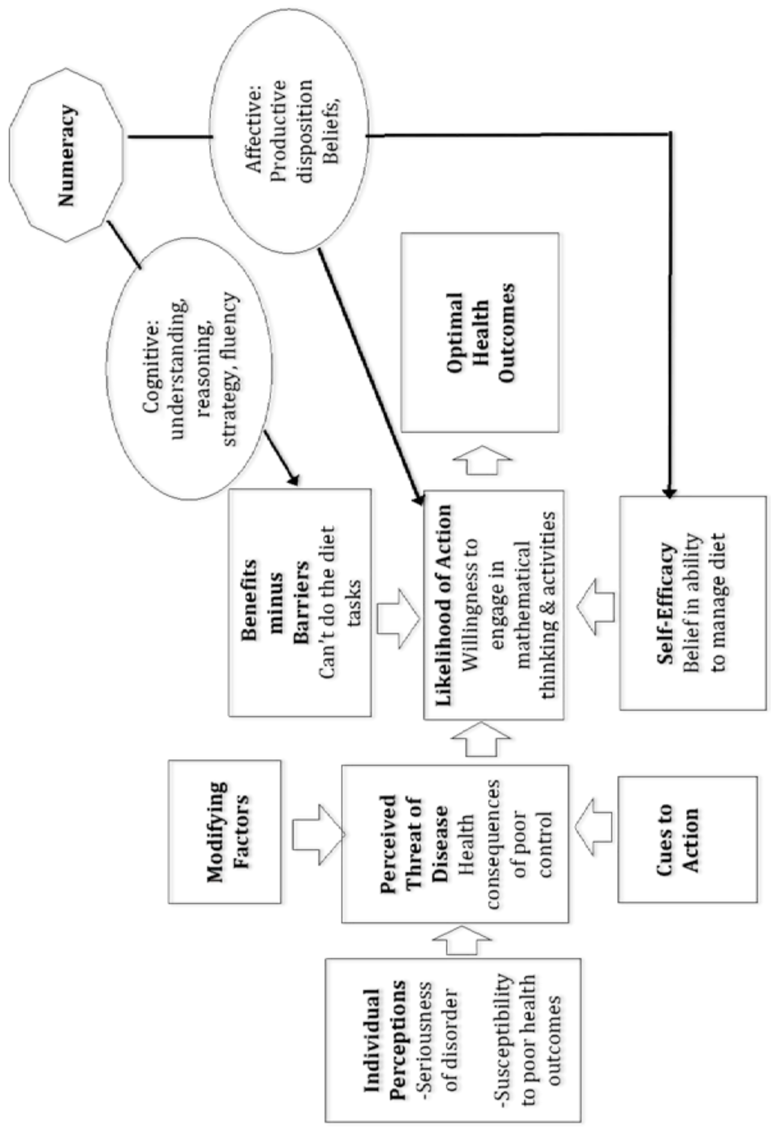


Figure 3. Health Belief Model Applied to Complex Diets




Numeracy
Cognitive: understanding, reasoning, strategy, fluency
Affective: Productive disposition Beliefs,
Optimal Health Outcomes
Benefits minus Barriers
Can't do the diet tasks
Likelihood of Action
Willingness to engage in mathematical thinking & activities
Self-Efficacy
Belief in ability to manage diet
Modifying Factors
Perceived Threat of Disease
Health consequences of poor control
Cues to Action
Individual Perceptions
-Seriousness of disorder
-Susceptibility to poor health outcomes

Measurement Tools

This study explored the pathways between numeracy and health outcomes. For each factor studied along the pathway, several measurement tools were available. An overview of tools used in health numeracy and related research reveals the best choices for this project.

Instruments measuring cognitive numeracy.

Cognitive numeracy in adults is measured in many disciplines, and both basic and applied tests are available. The most basic assessment of numeracy is a mathematics test. The mathematics sections of the Scholastic Aptitude Test, the Graduate Record Exam, and the computation section of the Test of Adult Education (CTB Research, 2013) assess basic math skills. Outside of school placement, the Wechsler Individual Achievement Test (WIAT) (Wechsler, 2005) and the Wide Range Achievement Test (WRAT) (Wilkinson, 2006) are norm-referenced performance measures of academic function, including mathematics. The math computation section of the WRAT includes counting, identifying numbers, and solving both oral and written math problems. Applied mathematics tests assess the ability to combine basic skills and use them in problem solving. The non-profit organization Comprehensive Adult Student Assessment System (CASAS, 2013) has created tests that assess math skills within practical contexts, which are sometimes used in adult education programs. For workplace skills assessment, math reasoning tools are available from groups such The Career and Technical Education Consortium of States (Virginia Department of Education, 2011).

Cognitive numeracy in the health literacy literature.

The health literature uses both basic and applied cognitive numeracy assessment tools, as described in Appendix D. Basic math tests such as versions of the WIAT and WRAT have been used directly in health numeracy evaluation (C. Y. Osborn et al., 2009) and to validate health numeracy assessment instruments (Parker, Baker, Williams, & Nurss, 1995; Marilyn M. Schapira et al., 2012). Applied numeracy tests are more common, many of which are imbedded in health literacy instruments. An early health literacy instrument, the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1993) tested word skills, but the Test of Functional Health Literacy in Adults (TOFHLA) (Parker et al., 1995) added a numeracy component. Designed to measure skills needed to understand situations encountered in the health environment, the TOFHLA begins with fifty reading comprehension questions, followed by seventeen numerical ability items. Test items are weighted such that literacy and numeracy figure equally in the final score. An abbreviated version, the S-TOFHLA, consists of only four numeracy items and fewer reading questions, to reduce average completion time from 22 to 12 minutes (D. W. Baker et al., 1999). The numeracy questions for the S-TOFHLA were chosen based on expected use in the health care setting: three concern understanding of time, and the fourth requires interpretation of a blood glucose level. As with most applied numeracy tests, the S-TOFHLA numeracy questions overlap with literacy skills, as reading is required to understand the questions.

More recent tools also require the combined use of numeracy and literacy skills to assess performance in functional settings. The Newest Vital Sign (NVS) requires locating information on a nutrition label, making calculations, and drawing conclusions from the results (C. Y. Osborn, Weiss, B.D., Davis, T.C., Skrepkauskas, S., Rodrigue, C., Bass, P.F., Wolf, M.S., 2011). NVS scores were highly correlated with S-TOFHLA scores. Since it is quicker and easier to administer, the NVS has been recommended as a patient screening tool for problems that may lead to poor dietary control in diabetes (Miser, 2013). The NVS has also been validated for use in the United Kingdom, with adjustment for differences in U.K. nutrition labeling (Rowlands et al., 2013). Another option is the 25-item Health Literacy Skills Instrument (HLSI) which includes a quantitative information section (McCormack, 2010). A shortened 10-item version has also been validated (Bann, McCormack, Berkman, & Squiers, 2012). A third tool is applicable to the current study as it assesses health literacy and numeracy of parents of young children (age <13 months). The Parental Health Literacy Assessment Test consists of 20 questions specific to care of this age group, including mixing infant formula, preparing over-the-counter medicines, understanding print material on breastfeeding, and interpreting nutrition labels; and a shortened version (PHLAT-10) has also been validated (Kumar et al., 2010). Although these tools include numeracy, they rely heavily on literacy skills, which would have introduced confounding factors in this study of numeracy in health outcomes.

Numeracy-only instruments.

In the health literature, a limited number of tools have been developed to measure only numeracy. Schwartz and Woloshin developed such a tool to measure participants' general understanding of probability and risk, and then compared it with their estimates of health risk. (L. M. Schwartz, Woloshin, Black, & Welch, 1997). Lipkus expanded this general tool by adding in questions about health risk (Lipkus et al., 2001). Participants struggled to complete either test, and the Subjective Numeracy Test (SNT) was developed to be a more palatable instrument (Fagerlin et al., 2007) (Zikmund-Fisher, Smith, Ubel, & Fagerlin, 2007). This tool is based on self-assessment, including perceived abilities to use percentages, such as in purchasing decisions, and preference for display of numerical information. The SNT has been criticized for the questionable validity of self-assessment to measure objective numeracy (Nelson W.I., 2013). The Numeracy Understanding in Medicine Instrument (NUMi) is another health numeracy tool that aims to assess a wide range of numeracy skills, but the content of 75% of the questions concerns probability and statistics (Marilyn M. Schapira et al., 2012). The Medical Data Interpretation Test is entirely about medical statistics (L. M. Schwartz, Woloshin, S., Welch, H.G., 2005). Most recently, Osborn et al developed the General Health Numeracy Test (GHNT) to assess a wide variety of numeracy skills. In the shortened version of six questions, three require risk perception calculations in percentages (C. Y. Osborn et al., 2013). Although these tests are focused on numeracy and require fewer literacy tasks than previously mentioned instruments, most of their content is irrelevant to the calculations required for planning of complex diets.

To narrow in on numeracy skills relative to routine medical management, a disease-specific tool has some advantages. The Asthma Numeracy Questionnaire, for instance, was developed to assess a patient's ability to understand and follow typical self-care instructions related to dosing medication and interpreting peak flow meter readings (A. J.

Apter, Cheng, J., Small, D., Bennett, I.M., Albert, X., Fein, D.G., George, M., Van Horne, S. , 2006). The management of diabetes requires both dietary calculations and determination of insulin dose and timing in response to blood glucose readings. The complexity of these numeracy tasks has prompted interest in an instrument specific to diabetes. A review of health literacy and numeracy tools for diabetes (Al Sayah, Williams, & Johnson, 2013) provides a succinct overview of the options. The Diabetes Numeracy Test (DNT) (M. M. Huizinga, T. A. Elasy, et al., 2008) was the first to be developed, and remains prominent in the literature. The original DNT consists of 43 items covering diabetes care and numeracy skills. Development of the tool took into consideration the wide range of numeracy skills present in adults with diabetes. A shortened version, the DNT-15, has good internal reliability with the original test. The DNT has been validated for use with adolescents (Mulvaney, Lilley, Cavanaugh, Pittel, & Rothman, 2013), and adapted for parents of children with diabetes (Pulgaron et al., 2014).

Strengths of the DNT are its strong correlation with WRAT (Cavanaugh et al., 2008) and measurement of applied skills for diabetes management tasks (C. Y. Osborn et al., 2009). In this study, even though numeracy was a variable and half of the participants were caretakers for a child with diabetes, the DNT, even the parental version, was not a usable measure of numeracy for several reasons. The scale is specific to diabetes and not readily adaptable to PKU. The DNT measures abilities of individuals who have been trained to manage diabetes, while the purpose of this study was to evaluate whether numeracy skills themselves are related to better health outcomes, and to the likelihood of staying engaged in the disease management process. A more fundamental test of numeracy was needed.

Cognitive instrument for this study.

Instruments for assessment of cognitive numeracy in the health literature frequently include portions of health literacy tools, and a few health numeracy measures. Neither provides an option appropriate for this study, as the former are tightly tied to literacy, and the latter are focused on risk assessment or a specific disease. A context-neutral, straightforward math test was most suitable for this research as 1) it could be applied across more than one health condition, 2) it could assess basic numerical abilities instead of the success of the patient education process, 3) it was appropriate for newly diagnosed individuals, and 4) it was applicable to path analysis which compared the relative impact of cognitive compared to affective pathways in health actions and outcomes. The WRAT, which has been used in several health numeracy and literacy studies as well as other areas of health literature, meets these criteria, making it the preferred tool for assessment of cognitive numeracy in this study. Although it does not assess skills in measurement, shapes, space or handling data, the WRAT measures nearly all of the number skills for both disorders as described in Tables 2 and 3.

Instruments measuring affective numeracy.

Unlike the cognitive instruments, which have been adapted to health literacy inquiries, affective numeracy assessment has stayed primarily within mathematics education, although it is at the intersection of mathematics, psychology, and education (Chamberlin, 2010). Numerous tools to assess affect have been created by math educators over several decades (McLeod, 1994). Appendix E provides an overview of several tools that have been singled out for their innovation, frequent use, and statistical testing (Chamberlin, 2010). Beyond education, math affect is relevant to any situation requiring numbers, including health management activities and decisions. Mathematics educators have created numerous tools to assess affect. This section will review math affect instruments that could be adapted for use in a health-related study.

Due to the perception that anxiety is the most significant emotion related to mathematics, anxiety is a prominent construct of nearly all scales measuring the affective component of numeracy. The Math Anxiety Rating Scale (MARS) as introduced in 1972 was a 98-item inventory (Richardson, 1972). The impact of anxiety on career choices in mathematics and related fields was a strong impetus for development of the scale. Participants are asked to rate on a five-point scale their expected level of anxiety when faced with mathematics-related situations. In the original author's 30-item revision of the MARS, more than half of the questions apply to the classroom setting, such as taking or thinking about mathematics tests, and the remainder refer to other situations requiring calculations, such as figuring sales tax or a dinner bill (Suinn & Winston, 2003). Neither the original MARS nor any of the shortened versions of it are suitable for a context unrelated to mathematics education. However, the descriptions of ordinary life situations could be considered similar to a parent's experience of facing numerical tasks related to a child's medical needs. Yet an instrument that measures more than the anxiety aspect of affect is more consistent with the concept of affective numeracy (Ginsburg, 2006) that was utilized in this study.

A broader view of numeracy affect underlies the Fennema-Sherman Mathematics Attitude Scale (FSMAS), developed to gain insight on females' learning of mathematics and course selection (Fennema, 1976). Widely used and adapted over many years, the instrument measures self-efficacy and motivation in addition to anxiety. While most of the nine sub-scales address constructs concerning the classroom or gender issues in mathematics, two subscales are relevant to this research: the Mathematics Anxiety Scale and the Effectance Motivation Scale in Mathematics. Each contains twelve items, with an equal number of positively and negatively worded questions, and a choice of five responses from Strongly Agree to Strongly Disagree. Another strength of the FSMAS is its use of bidirectional constructs. Among the emotional responses to math, reactions to particular problems can be motivating forces in either direction: the positive experience of solving a problem encourages further engagement, while the negative experience of frustration can foster avoidance of similar situations in the future (McLeod, 1994). The MAS includes both ends of the spectrum of affective responses to mathematics. It includes positively worded items such as "I find math interesting," which gives a broader picture of affective numeracy (Bai, 2008). The affective numeracy instrument developed for this study utilized questions from the two relevant subscales of the FSMAS, which already included several questions that were applicable to this study. Of the questions that applied only to the learning of mathematics, several were adapted to measure the use of numeracy in life applications instead.

Measures of self-efficacy.

Self-efficacy scales have been used in many areas of study to gauge confidence in ability to perform a specific behavior (Pajares, 2009). The Perceived Self-Confidence Scale was developed and standardized in the mid-1990's to evaluate self-efficacy in a wide range of domains (M. S. Smith, Wallston, & Smith, 1995). In a health application, it was adapted to create the Perceived Medical-Condition Self-Management Scale (PMCSM), a template that can also be used with any medical adult condition requiring self-management by inserting the name of the condition into each item of the scale. No self-efficacy scales have been created for PKU, but many diabetes-specific self-efficacy instruments have been developed over several decades (van der Bilj, 1999) (Sarkar, 2006). The PMCSM has been applied to diabetes to create the Perceived Diabetes Self-Management Scale (PDSMS) (Wallston, Rothman, & Cherrington, 2007). It presents eight questions about perceived competence at diabetes-related tasks that are rated on a five-item (Cavanaugh et al., 2009; Green, Rothman, & Cavanaugh, 2012; C. Y. Osborn et al., 2010; White, Osborn, Gebretsadik, Kripalani, & Rothman, 2011). A scale to measure diabetes-related self-efficacy is also available for youth with T1D or type 2 diabetes (Cullen, Anderson, McKay, & Watson, 2007).

Parenting a child with a health condition introduces different competencies and different behavioral goals than adult self-management. Instruments to measure self-efficacy of parents caring for children include tools for parenting of newborns (Bryanton, 2008) and toddlers (Coleman, 2003). For children with diabetes, a scale developed for mothers of children with diabetes ages 8 to 17 years (Leonard, Skay, & Rheinberger, 1998) has been used to study maternal environment and the child's diabetes self-efficacy (Marvicsin, 2008). The Self-Efficacy for Diabetes Scale for adults (Grossman, Brink, & Hauser, 1987) was adapted for parental self-efficacy in a study of parent stress in childhood diabetes (R. Streisand, Swift, Wickmark, Chen, & Holmes, 2005; R. Streisand, Swift, E., Wickmark, T., Chen, R., Holmes, C.S., 2005), and used to study effectiveness of an online support program for parents of children with T1D (Merkel, 2012). Recently, the Perceived Diabetes Self-Management Scale was adapted and validated for use with parents of young children with T1D (Marchante, 2013). This scale, the Parental Self-Efficacy for Diabetes Management Scale, was administered to parents of children with T1D to measure self-efficacy in this study. For parents of children with PKU, the scale for diabetes was adapted by changing "diabetes" to "PKU" in each question. This adaptation was justified by the generic wording of the items of the scale, and its origin in a scale for any medical condition.

Measures of metabolic control and engagement.

In diabetes of all types, $A1_C$ is the standard indicator of metabolic control over the previous 2-3 months. The most recent $A1_C$ result is typically the sole measure of control (Hassan & Heptulla, 2010), (C. Y. Osborn et al., 2010), (Pulgaron et al., 2014). Daily self-management of T1D includes measurement of blood glucose several times a day. Most glucose meters record data on each blood glucose reading, and this data can be accessed by clinicians. Frequency of blood monitoring reflects a parent's engagement in prescribed diabetes care, as failure to obtain sufficient blood glucose levels potentially results in ineffective treatment (Given, O'Kane, Bunting, & Coates, 2013).

Metabolic control in PKU is evaluated by periodic blood phenylalanine levels. While a few researchers have used the one most recent phe level to reflect control (Cotugno et al., 2011), (Ievers-Landis, 2005), most studies assess levels over at least six months (MacDonald et al., 2010), to as long as several years (Bekhof et al., 2003), (Walter, 2002), or lifetime (Waisbren et al., 2007). Freehauf and colleagues measured control by comparing phe levels in the previous five years to target levels set by the clinic (Freehauf et al., 2013). The median and the mean of the differences correlated well (Spearman $\rho=0.92$, $p<0.01$). Others have measured the median percentage of blood concentrations meeting the target range (MacDonald et al., 2010).

No single measure characterizes compliance with treatment (MacDonald et al., 2010), and several authors consider the number of blood specimens submitted as a useful indicator of adherence to clinic expectations (Walter, 2002), (MacDonald et al., 2010). One study compared this measure to blood levels, and found no significant relationship between the two measures, suggesting that blood levels and the number of specimens submitted are unrelated (Freehauf et al., 2013). As outcome variables, blood levels indicate metabolic control, while frequency of blood specimens reflects the submitter's engagement in the process of monitoring the success of the treatment. In this study, blood levels served as an indicator of adherence to diet, which was not measured per se. Engagement was evaluated by frequency of submission of blood levels, which served as a proxy for engagement in diet management.

Conclusion

Health literacy and numeracy are important in health outcomes, and may act as social determinants of health. Complex diets for children are difficult to manage, and many families are unsuccessful at adhering to the diet instructions they have been given. Numeracy is particularly fundamental to complex diet management yet research is needed to clarify ways to enhance success for caretakers with limited skills in this domain.

Numeracy includes not only cognitive skills, but also affective ones that may influence the peripheral aspects of using numbers in diet-related tasks. This study examined the relationship between numeracy and diet treatment success. Questions addressed included the degree to which parent numeracy is related to achievement of treatment goals. Does numeracy act as a direct barrier to diet management due to cognitive skill differences? Or does numeracy foster indirect barriers to diet adherence via affective pathways, or self-efficacy? Are demographic and social characteristics significant factors on this pathway?

Two health conditions that require complex diets: type 1 diabetes, and phenylketonuria, were the subject of this study of the relationship between parental numeracy and child health outcomes. This research provides a deeper understanding of the numeracy-based barriers to optimal health outcomes, and it may inform the education and guidance of parents who manage their children's complex diets. On a broader scale, understanding of the factors that influence the pathway between numeracy and health outcomes may be applicable to other health issues centered on diet, such as adult and pediatric obesity.

CHAPTER III

METHODS

The literature provides a foundation of careful research as background for this study of numeracy and self-efficacy in parents of children with type 1 diabetes (T1D) or phenylketonuria (PKU). As this study filled in a gap in our understanding of the pathway between numeracy, self-efficacy, and disease outcomes, it employed some of the research methods, instruments and strategies utilized by other researchers studying literacy, numeracy, and chronic disease, particularly diabetes. Some instruments required adaptation to the subject at hand while retaining the fundamental properties of the original tool.

This study analyzed the pathway between numeracy and health outcomes in T1D and PKU, specifically the role of self-efficacy in this relationship. The null hypothesis was that lower parental cognitive and affective numeracy have no effect on self-efficacy, engagement in disease monitoring, or health outcomes.

Setting and Study Participants

This research utilized a cross-sectional design and a convenience sample of parents in East Central States whose children receive medical services for T1D or PKU. Most children with these diagnoses are treated at specialty care outpatient clinics that serve families from large geographical domains including urban, suburban, and rural areas. Parents were invited to participate in the study by the professional staff at their clinic, by the researcher, research assistant, or organizers of community events for families of children with a particular disorder. A recruitment tool (Appendix F) was created to be sent prior to the community event to families who were registered to attend, or to be given by hand to parents at the event or at clinic appointments. Clinic personnel also distributed the recruitment tools by hand or by email. Recruitment continued until 100 parents were enrolled, consisting of 50 parents of children with T1D and 50 parents of children with PKU.

Participants in the study were caretakers who have primary responsibility for the dietary and medical care of a child age one to twelve years who has a diagnosis of classic phenylketonuria or type 1 diabetes. Certain test instruments were not available in foreign languages; therefore participants had to be literate in English. Parents of children with milder forms of PKU such as hyperphenylalanemia were excluded due to differences in the level of dietary restriction required for treatment. Prior to scheduling the interview, parents were asked if the child had this diagnosis, and it was confirmed with the clinic staff. Parents of children with T1D were eligible for the study if they were literate in English, and their child had been diagnosed with T1D for at least one year. Parents of children with PKU were eligible if they were literate in English, and their child had not been on the medication Kuvan during the previous six months, as it usually permits a more liberal diet. Parents of children with either T1D or PKU were excluded if they were unable to schedule an interview at one of the locations offered (the child's clinic, at a community event, or a designated location in the community).

Approval for the research was obtained from the Institutional Review Board at the University of Louisville, and from the universities that sponsor clinic programs at which data was collected. All research personnel successfully completed HIPAA and CITI training.

Data and Procedures

Informed consent was obtained from all participants, using a format approved by the Institutional Review Boards. Participants signed a waiver to allow their child's medical clinic to release data to the researcher on blood levels measured in the past 6 months, as well as the number of blood specimens the clinic had recommended during that time period.

Data on clinical outcomes was collected from clinic records as follows:

PKU: The blood phenylalanine levels from all specimens submitted in the 6 months prior to the interview were obtained from the child's clinic. A minimum of two levels was collected, even if that required a time span longer than 6 months. The median and standard deviation of the differences between each blood level and the upper end of the target range was calculated (Freehauf et al., 2013).

T1D: Mean A_{1c} levels for the 6 months prior to the interview were obtained from the child's clinic. Since $A1_C$ is an indicator of blood glucose levels over the previous two to three months, two $A1_C$ levels were collected and the mean was calculated. Although most research studies use a single $A1_C$ value to assess glycemic control (Hassan & Heptulla, 2010), (C. Y. Osborn et al., 2010),(Pulgaron et al., 2014), a 6-month period was evaluated to measure control over a longer period of time. In addition, the mean, minimum, maximum, and standard deviation of blood glucose levels evaluated at home in the previous 6 months were obtained using data downloaded from each patient's glucometer.

To measure engagement, the frequency of blood sampling in the home (blood spots on filter paper for children with PKU, and blood tests using a glucometer for children with T1D) was compared to the number requested by the clinic (Walter, 2002), (Freehauf et al., 2013) over the 6-month period. Engagement was calculated as the number of blood levels taken as a percentage of the number recommended by the clinic. In the 6-month period, "weekly was defined as 6 levels, "every other week" was defined as 12 levels, and "every week" was defined as 25 levels.

Most participants recruited at clinics were interviewed in a quiet, confidential location in the clinic area, such as a small meeting room. By necessity, some interviews occurred in an examining room or a quiet corner of a waiting area. Participants recruited at community events were interviewed in a quiet, confidential location at the event when possible, or at a table during unscheduled portions of the conference. Some parents recruited at either setting chose to arrange an interview at another designated location in the community, such a public library or in the home. The researcher administered all testing instruments. Completion time was to be 30 to 40 minutes. Parents were compensated for the time spent participating in the project. In the first three months of data collection, parents received a lunch box kit for themselves or their child. During the remaining months, a gift card for a discount department store was offered as an alternative compensation.

Participants completed three instruments: 1) the mathematics computation section of the Wide Range Achievement Test 4 (Wilkinson, 2006), 2) the Parental Self-Efficacy Scale for Diabetes Management (Appendix G) (Marchante, 2013) or the Parental Self-Efficacy Scale for PKU Management (Appendix H), and 3) the Daily-Life Mathematics Attitude Test (Appendix I). They also completed a demographic form (Appendices J and K) with questions about household income, parent's age, parent's last year of schooling, parent race, child's age, and number of years parent has managed the child's dietary treatment. Questions were worded similarly to the format of the General Social Survey (T. W. Smith, Marsden, P., Hout, M., Kim, J., 2013). Verbal assistance with the form was provided on request. For children with T1D, the clinic provided information on whether insulin was administered by injection or by an insulin pump. The interview did not include questions on parents' feelings about managing their children's diets or the use of math, but several parents offered comments, which were noted.

Measures

Numeracy – Cognitive Component

The Wide Range Achievement Test: Fourth Edition (WRAT4) (Wilkinson, 2006) is the most recent edition of a validated instrument that quickly accesses basic academic skills. The Math Competency section of the WRAT4, an oral and written test of mathematics problems, was chosen for this study as it is context-neutral and measures basic numeracy skills as opposed to the content of a specific patient education curriculum. Thus it applies to either PKU or T1D, and measures most of the number skills required for management of either disorder. Raw scores can be converted either to age-based or grade-based standard scores. The content of the WRAT4 is protected by copyright, and the testing materials are only sold to appropriately qualified trained professionals who will be using or supervising the use of the instrument. The researcher was be trained to administer the test and was supervised by an authorized and experienced clinical psychologist. The researcher administered the test to all participants. As designated by the testing protocol, participants were allowed 15 minutes to answer the questions.

Numeracy – Affective Component

An adapted version of the Fennema-Sherman Mathematics Attitude Scales (FSMAS) (Fennema, 1976) was used to measure the affective component of numeracy. The FSMAS, which has been widely used in assessing math attitudes of students across levels of the mathematics curriculum, was especially appropriate for this study for two reasons. First, it includes both positive and negative affective responses to mathematics to provide a broad picture of affective numeracy (Bai, 2008). Secondly, of the nine scales that comprise the instrument, two are directly applicable to this study: Mathematics Anxiety Scale and Effectance Motivation in Mathematics Scale. The adapted instrument, the Daily-Life Mathematics Attitude Scale, was created by altering statements in the FSMAS that applied only to the learning of mathematics to become statements that relate to general math-related situations and problems outside the classroom environment. To reinforce this context, the new instrument included images of every-day applications of mathematics, such as the examples used in the Subjective Numeracy Scale (Fagerlin et al., 2007). For example, the FSMAS item "I get a sinking feeling when I think of trying a hard math problem" was changed slightly to " I get a sinking feeling when I think of trying to figure out a hard situation using numbers." Items specific to the classroom, such as "I usually have been at ease during math tests," were omitted. The Daily-Life Mathematics Attitude Scale (DLMAS) includes 16 questions, half of which are reverse-scored (Appendix I). The labels for the Likert scale were changed slightly for the sake of clarity and simplicity.

Validity and Reliability Testing: The construct and criterion validity considerations for the original FSMAS were specific to math education and not applicable to the use of the instrument in this study. However, the test has an established history of use over four decades as a measure of math anxiety and affect. Content validity of the DLMAS was evaluated in two steps. For qualitative assessment, the researcher administered the instrument to 17 parents of children with PKU or T1D of any age, in a one-on-one interview in settings similar to the actual data collection. After each question, the parents were asked whether the item represented mathematics attitudes and/or anxiety, and why they chose a particular answer. A consensus of the responses informed changes to the instrument. These parents were not included in data collection for the study.

Quantitative validity testing used a panel of jurors, composed of ten individuals including present and former teachers of standard and remedial math courses at a community college, math teachers in a high school diploma equivalency program, adult education specialists, and developmental psychologists. The jurors received the instrument by email or in person.

They were asked to rate each statement according to how strongly they felt it captured attitudes toward mathematics and math anxiety, using a 5-point Likert scale from "strongly agree" to "strongly disagree." Content validity ratio and statistical significance were the basis for revisions to the instrument. Reliability testing was conducted following data collection. Cronbach's alpha was used to evaluate internal reliability of the DLMAS.

Self-Efficacy of Disease Management

This study required a parental self-efficacy scale for parents of young children with diabetes or PKU. The Parental Self-Efficacy Scale for Diabetes Management (PSESDM) is an 8-item scale for measurement of self-efficacy in parents of children with diabetes (Marchante, 2013). Responses are rated on a 5-point Likert scale, for 1="Strongly Disagree" to 5="Strongly Agree." Four of the items are reverse scored, and total score ranges from 8 to 40. Higher scores represent higher parental self-efficacy. The scale was validated among parents of children ages 2 to 9 with T1D. Internal consistency using

Cronbach's alpha was adequate (α=.84). Criterion-related validity was assessed by comparison with measurement of youth diabetes-related quality of life and with glycemic control, based on previous studies linking youth self-efficacy to these factors (Grossman et al., 1987) (Iannotti, 2005) (Grey, Boland, Yu, Sullivan-Bolyai, & Tamborlane, 1998), and evidence linking parental self-efficacy to successful outcomes in young children (Leonard et al., 1998), (R. Streisand et al., 2005). Based on these criteria, validity was considered acceptable, as higher PSESDM results were associated with higher scores on a measure of child quality of life ($r=.41$, $p=.002$) and with lower $A1_C$ levels ($r=-.25$, $p=.048$) (Marchante, 2013). The authors granted permission to the researcher to administer the instrument to parents of children with T1D in this study. The instrument for parents of children with PKU was nearly identical, except for the use of "PKU" in place of "diabetes" in each question. The PSESDM and the revised version for PKU, the Parental Self-Efficacy Scale for PKU Management (PSESPM) are shown in Appendices G and H, respectively. The internal reliability of the PSESPM was evaluated using Cronbach's alpha, and compared to the internal reliability of the PSEDPM in this study.

Statistical Analysis

A causal model is a heuristic device to represent the relationships among variables (Asher, 1976). Using structural equation modeling, the magnitude of the linkages between variables can be estimated to provide information about the underlying causal relationships. The strength of each relationship can differentiate whether variables are potential determinants of effect, or irrelevant, or impinged upon by yet another variable. The causal model for this study (Figure 5) includes many variables relevant to the relationship between numeracy and clinical outcomes in this population, as identified in the literature. Figure 6 is a model of the relationships that were measured in this study. This research project measured two dependent variables: health outcome based on clinical lab results, and engagement based on frequency of engaging in clinical measures. Higher values on lab results correspond with negative health outcomes. The independent variables included one latent variable (numeracy) and six measured variables (WRAT4 scores, math attitudes, self-efficacy scores, income, last year of education completed, and age of parent). A minimum sample size of 87 was required to run this model. Structural equation modeling has been used by Osborn et al to evaluate the role of diabetes self-efficacy on the pathway between numeracy or literacy and glycemic control in adults (C. Y. Osborn et al., 2010). Pathway analysis identified the greater strength of numeracy over health literacy in predicting self-efficacy, and the significant relationship between self-efficacy and glycemic control. This study also used structural equation modeling. Like the Osborn study it included numeracy, self-efficacy, and clinical outcomes, but this research also differentiated between cognitive and affective numeracy, it included both laboratory data and a measure of engagement, and the population was parents of children with T1D or PKU. Data was analyzed using IBM SPSS Statistics 22 and IBM® SPSS® AMOS 22™.

Figure 5. Causal Model - All Variables

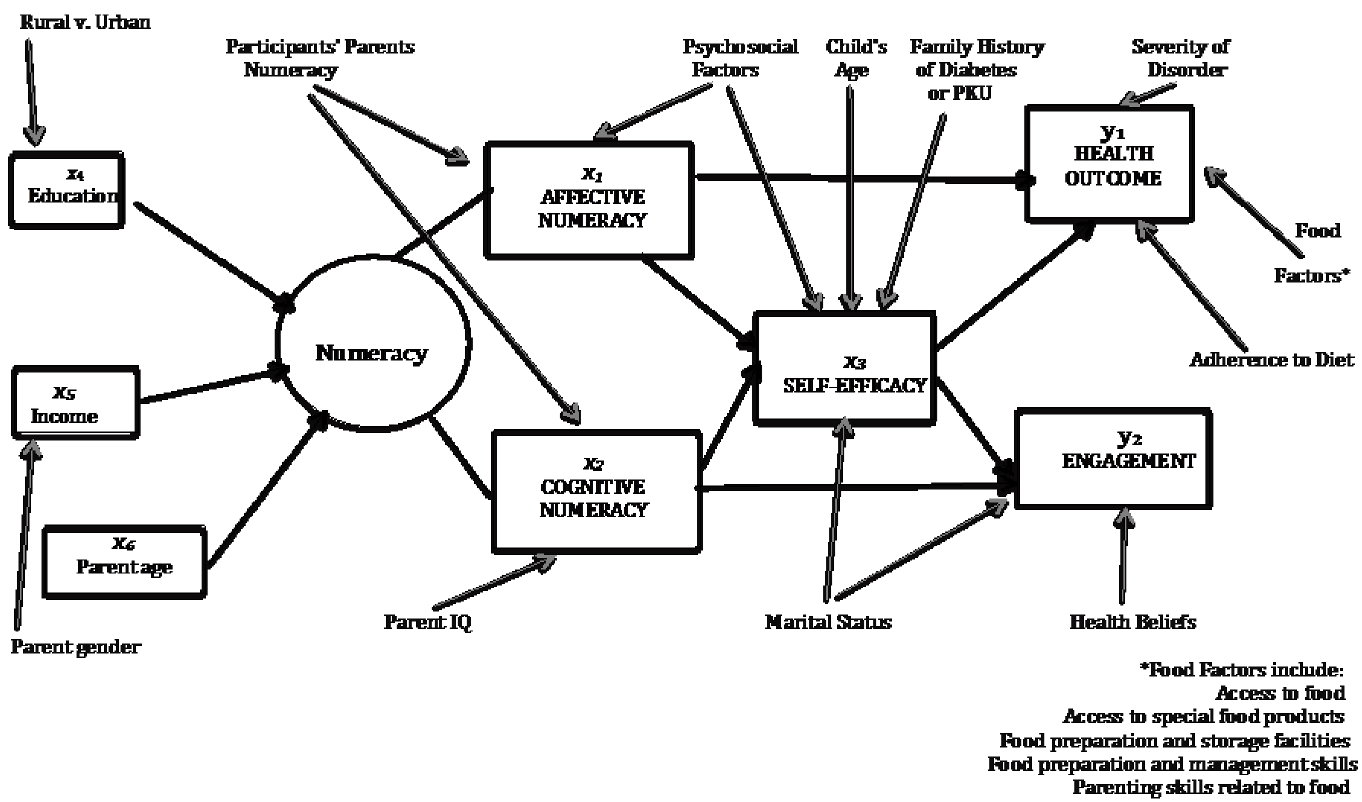
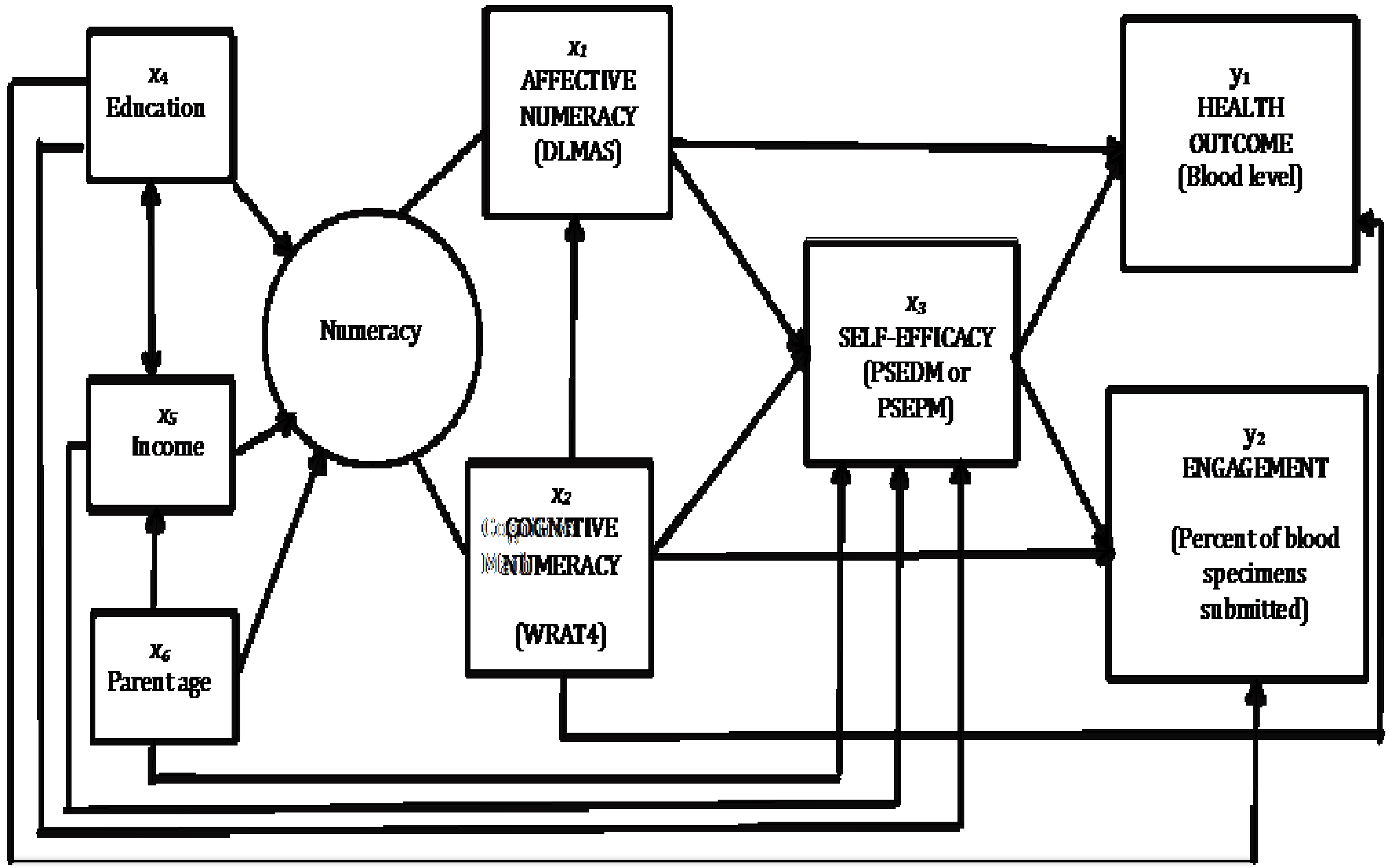


Figure 6. Causal Model - Variables To Be Measured



CHAPTER IV

RESULTS

The purpose of this study was to examine the relationship between parental numeracy and health outcomes of children on complex diets. Two conditions requiring complex diets, type one diabetes (T1D) and phenylketonuria (PKU), were chosen for the research as they have measurable indicators of metabolic control that depends on diet, and their incidence is independent of health behaviors in the child or family.
The intent was to explore the specific roles of both cognitive and affective numeracy on maintaining metabolic control, and engaging in the process of in-home monitoring, with self-efficacy as a possible covariate. The Health Belief Model was the theoretical basis for this exploration, as self-efficacy is a key construct, and numeracy is related to the factors of barriers and likelihood of health behaviors that are key to health outcomes.

Peripheral factors of parental education, family income, parent and child age, and duration of diet management were also measured as possible determinants of health that are relevant to this process. Demographic data were collected to characterize the sample and to evaluate whether the patient samples from the two disorders were comparable. Unique to this study was the consideration of both cognitive and affective numeracy, the measurement of engagement in health-monitoring tasks, and the use of structural equation modeling to evaluate relationships among variables.

Participants

Parents of children with the diagnosis T1D were recruited at a tertiary level pediatric endocrinology clinic. Recruitment for parents of children with PKU took place at three clinics specializing in genetics and metabolic disorders, and at seven community events for families of children with PKU. Children in the latter families received specialty medical care at clinics affiliated with eight additional hospitals or programs. Enrollment occurred in a 5-state (KY, OH, IN, TN and IL) area of East-Central states.

Parents were approached about participating in the study using the IRB-approved recruitment flyer, or a verbal invitation that included the same information. Clinicians and support staff at clinics, leaders of community events, or the investigator conducted recruitment. The most common reason stated for participating was to "help out," and the most common reason stated for not participating was lack of time to complete the study instruments. The recruitment flyer was purposefully vague about the questionnaires that participants would complete, to assure that parents with poor numeracy skills or negative affects about mathematics would not be reluctant to participate. Recruitment occurred between June, 2014 and February, 2015.

Participant characteristics.

One hundred parents agreed to participate in the study and signed the IRB-approved informed consent and HIPPA-compliant release form; 98 completed the study instruments. Demographic characteristics of the participants are listed by diagnosis in Table 2.

Table 1. Characteristics of Study Participants by Child Diagnosis

Characteristic	Total sample n=98	PKU n=48	T1D n=50
Affective Numeracy Score, M (SD) (range 14-70)	31.4 (13.7)	28.9 (12.7)	33.8 (14.3)
Cognitive Numeracy Score, M (SD) (Standard for age)	95.4 (14.5)	94.0 (16.2)	96.7 (12.6)
Self Efficacy Score, M (SD) (range 8-40)	32.7 (5.0)	32.4 (5.5)	33.0 (4.5)
Engagement: % blood tests completed	73 (37)	66.9 (33.8)	78.5 (39.1)
Health Outcome:			
Mean Blood level, M (SD)	A1c Equiv 7.8 (1.3)	Phe 5.3 (2.8)	A1c 8.3 (1.1)
Length on diet, yrs M (SD)	5(2.9)	6.1(3.3)	4.1(2.0)
Sample Demographic Data			
Child's Age, yrs, M (SD)	7.3 (3.1)	5.9(3.2)	8.7(2.4)
Parent's Age, yrs, M (SD)	37.0 (8.3)	36.1(9.3)	37.8(7.1)
Parent's Race, n (%)			
White	93(91.2)	45(93.8)	48(96.0)
Black	1 (1.0)	0 (0)	1 (2.0)
Latino/Hispanic	2 (2.0)	2 (4.2)	0 (0)
Native American	1 (1.0)	1 (2.0)	0 (0)
Residence Location, n (%)			
Big city	11(10.8)	7(14.6)	4 (8.0)
Suburb, outskirts	26 (25.5)	16(33.3)	10 (20.0)
Medium-sized city or town	22 (21.6)	8(16.7)	14(28.0)
Small town	18(17.6)	8(16.7)	10(20.0)
Farm or country	20(19.6)	8(16.7)	12(20.0)
Type of Health Insurance n (%)			
Public	39(38.2)	24(50.0)	15(30.0)
Private	56(54.9)	21(43.8)	35(70.0)
None	3(2.9)	3(6.3)	0(0)
Income, median	$67,500	$62,500	$75,000
Range	$2,500 to >$250,000		
Education, yrs M (SD)	14.5(3.1)	14.3(3.6)	14.8(2.5)

The characteristics of the children with each disorder, and their parents, were similar in most respects, including parent age and education, and household size. As expected, the race of both groups was predominantly but not entirely white. Due to the typical age at diagnosis, children with PKU had been on a special diet for a longer time. The children with T1D were somewhat older, more likely to have private insurance, and their families had greater income. More children with PKU lived in large cities or suburbs, perhaps due to data collection at PKU community events held in urban areas. At community events, fewer than 5 parents of children with PKU were interested in participating but ineligible because their child was on the medicine Kuvan. This situation was avoided by stating the criteria for inclusion at the first time the study was mentioned to parents. In clinic settings, staff only referred parents whose children had not been on Kuvan in the preceding six months.

Preparation of Data for Analysis

Raw scores on the Wide-Ranging Achievement Test (WRAT-4) were converted to standard scores for age using tables included in the instrument manual. Standard scores on the WRAT are based on mean of 100 and a standard deviation of 15. Items on the test are ordered from simplest to most complex. Some of the more difficult questions assessed math skills that are beyond those needed for disease management. These more difficult items included solving for variables, understanding basic statistical terms, and multiplication or division using decimals, which could have been done easily with a hand calculator. Thus a person with a high score is very proficient at math, but a person with a moderate score would also be skilled enough for disease management, especially if a hand calculator were available.

In Daily Life Mathematics Attitude Scale (DLMAS) scoring, a high score represented more anxiety or negative feelings concerning math. For clarity in describing the relationship to other variables, DLMAS was converted to the variable Comfort by subtracting the score from the total possible score of 70. Thus, a high score on Comfort reflects a person with a positive affect toward mathematics and a low level of anxiety.

Unifying measures of PKU and T1D control.

To combine health outcome data for the two diagnoses into one variable, a process was devised to convert phenylalanine levels to a scale that matched A1c values, even though physiologically the two measures are unrelated. Using recently published management guidelines for each disorder, key blood levels were identified that mark cut-offs between desirable and harmful blood levels, beginning with the goal of phenylalanine ≤6.0 mg/dL for PKU (Vockley et al., 2014)and the goal of A1c ≤ 7.5% in T1D (Chiang et al., 2014).

A very high level that represented extremely poor control for each condition was identified based on research suggesting the point at which very high phenylalanine (phe) levels cause significant drops in IQ scores (Waisbren et al., 2007) and very high blood glucose levels cause serious microvasculature damage (Chiang et al., 2014). American Diabetes Association reference on metabolic control for adults with diabetes was also taken into consideration (American Diabetes Association, 2006). Comparable low levels for each disorder were based on expected values for persons without a disorder: phenylalanine 0.1 - 0.5 mg/dL, and A1c 4.5 to 5.0%.

A linear regression equation was calculated based on these points. A physician specialist for each disorder was asked to describe the values they used clinically to differentiate fair, poor, and very poor control. These labels correlated well on the regression line. The following equation was used to convert phe levels to an equivalent A1c value:

Unified T1D/PKU blood value = 0.4643 (Phe) + 4.7143.

A high blood value represents poor health outcome due to high blood levels of harmful metabolites.

Unification of high blood levels.

Since any phe levels under 6.0 and any A1c levels under 7.5 is generally considered acceptable, a variable was created to study whether any factor explained the difference between cases with "good" levels and those that were poor or very poor. The variable AboveGoal was calculated as A1c minus 7.5, and phe minus 6 adjusted to and A1c equivalent. All negative values were changed to zero. This adjustment has been made by other authors in interpreting blood level outcome data (Freehauf et al., 2013).

Validity determination.

Qualitative evaluation of the Daily-Life Mathematics Attitude Scale by 17 parents of children with PKU or T1D identified two items that were difficult to answer as they contained double negatives. These statements were reworded to avoid confusion. Based on parent comments, several questions were reworded to simplify them for better understanding. The final version was worded so it contained an equal number of items that were scored positively and negatively.

Several parents commented that they hated math, but some added that they were willing to do it for their child's health. Others stated that they liked math and did well with it in school. When asked what they were thinking about when completing the instrument, the most common answers were helping a child with math homework, using math at work, or balancing a checkbook. Only two persons mentioned the use of math in diet management. All respondents replied positively when asked whether the questionnaire represented math attitude and anxiety.

In quantitative validity testing, the content validity ratio for each question was based on the proportion of jurors who agreed or strongly agreed that the statement captured attitudes toward mathematics and math anxiety. To reach an acceptable content validity index as described by Lawshe (Lawshe, 1975) and Wilson (Wilson, 2012), two questions (numbers 9 and 13) were omitted from the scoring of the questionnaires (Appendix A) after data collection.

Internal reliability of the mathematics affect instrument was very high (Cronbach's alpha = .95). The self-efficacy scales for PKU and T1D combined also had acceptable internal reliability (Cronbach's alpha =.828).

Relationships Between Key Variables

Bivariate analysis was used to characterize relationships between key variables. Results of analysis are given in Table 2.

Table 2. Bivariate Correlations

	Blood Levels	Above Goal	Engage-ment	Math Score	Comfort with Math	Self-Efficacy	Educa-tion	Inco me
Above Goal	.748 ***							
Engage-ment	-.103	-.227*						
Math Score	-.160	-.322**	.146					
Comfort with Math	-.150	-.052	-.097	.533***				
Self-Efficacy	-.273**	-.269**	.169	.100	.103			
Education	-.154	-.313**	.180	.566***	.225**	.019		
Income	-.249**	-.345**	.163	.532***	.311**	.105	.548***	
Diet Length	.146	.215*	-.116	.092	.189	-.368***	-.070	.099

Pearson correlation coefficients

Significance (2-tailed): *** indicates P<.001, ** indicates P<.05, * indicates P<.01

Blood levels were negatively related to income and self-efficacy (P<.001). When blood levels above goal were the point of comparison, math score, engagement, and education also reached significance. Cognitive math scores were significantly associated with comfort with math, as well as with education and income. Comfort with math was also related to education and income. Education and income were highly related. The number of years a child had been on the special diet was negatively related to self-efficacy ($P<.001$).

Associations Between Peripheral Variables and Health Outcome Indicators

Demographic data on type of community and type of insurance was collected to characterize the sample, and to provide additional perspective on relationships between these factors and health outcome indicators. A chart of the associations of means is provided in Appendix L. Type of community of residence was associated with significant differences in blood levels in general as well as with blood levels above goal. Residents of big cities had the lowest mean blood levels, while children from small towns or farms had higher mean levels. Children with private and public insurance did not differ significantly in their overall metabolic control, but when compared in terms of levels above goal, children with public insurance were significantly more likely to have higher blood levels.

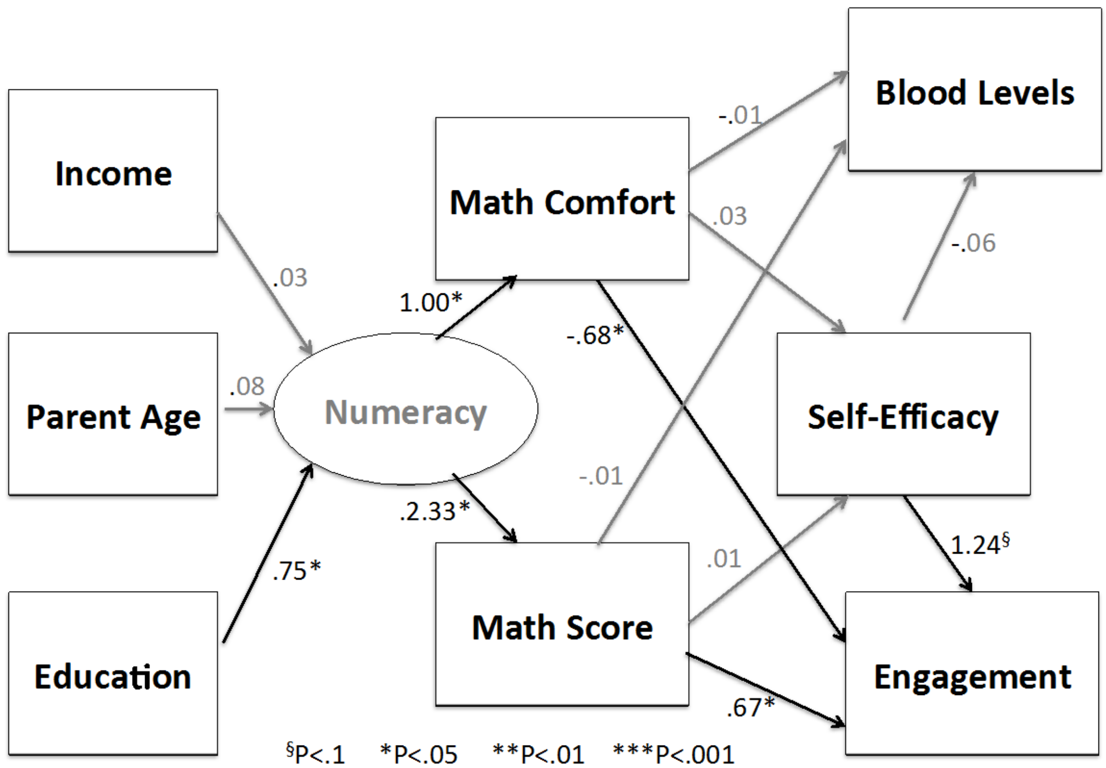
Structural Equation Models

Beyond associations between pairs of variables, structural equation modeling (SEM) tested the relationships among the collection variables based on the hypothesized pathway depicted in Figure 6. The direction and magnitude of pathway weights describe relationships between variables while accounting for effects of factors that precede them in the model. A path weight greater than 1.0 indicates a high degree of collinearity in the relationship. Model fit assesses how well the model compares to the observed covariances. It is evaluated via Chi-Square goodness of fit statistic, with a significant chi-square indicating lack of satisfactory model fit. Measures of acceptable fit between the model and the data are indicated by chi square/degree of freedom ratio in the range of 2:1 to 3:1, normal fit index above 0.9, relative fit index between close to 1.0 and incremental fit index greater than .90.

SEM also allowed for the inclusion of the latent (hidden) variable, numeracy. Factor analysis was conducted on the two components of numeracy. The combination of both cognitive and affective aspects (math scores and math comfort) accounts for 25% of the variation in the variable "numeracy." Path weights indicated that cognitive numeracy more strongly predicts general numeracy than does math comfort.

Model 1 is the causal model of the predicted pathway measured in this study, as evaluated using IBM® SPSS® Amos 22™ (Figure 7). It includes six measured variables (math score, math comfort, self-efficacy, income, parent age, and education), one latent variable (numeracy), and two outcome variables (metabolic control and engagement). Of these, the exogenous variables (of external origin) are income, education, and parent age, while remaining variables are endogenous, as they are influenced by effects of other variable, and in turn may have effects further along the pathway. This SEM tested whether numeracy predicted blood levels or engagement via self-efficacy after controlling for income, parent age, and education. Examination of path coefficients indicated that neither of the two numeracy measures was associated with blood levels,

Figure 7. Pathway Model 1

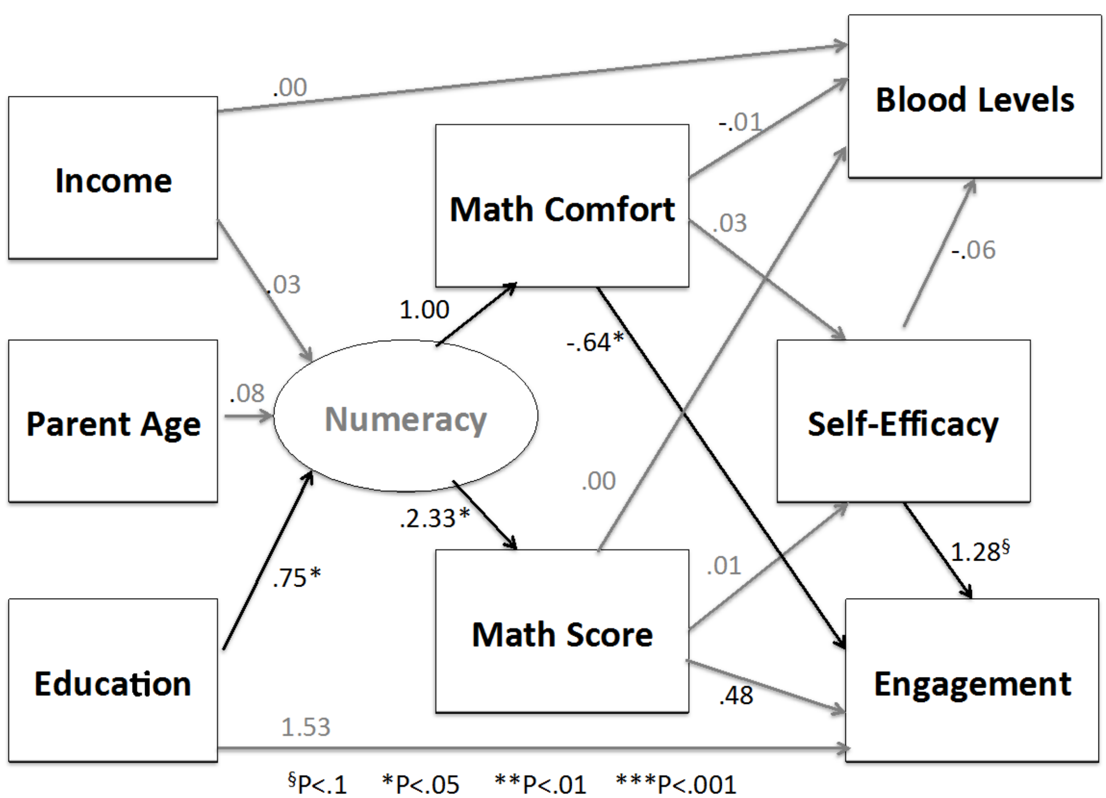


nor did they predict self-efficacy. Income and parent age did not impact numeracy, but education was positively associated with numeracy (r=.75, P<.05). The two components of numeracy were predictors of engagement in opposite directions: math score was a positive predictor (r=.67, P<.05) and math comfort was negatively related (r=-.68, P<.05).

In model fit analysis, a significant chi square (P<.000) indicated lack of a satisfactory model. All other model fit statistics (chi square/degree of freedom ratio 4:1, normal fit index .627, relative fit index .105, and incremental fit index .692) concurred that the model could be improved substantially by adding other covariates.

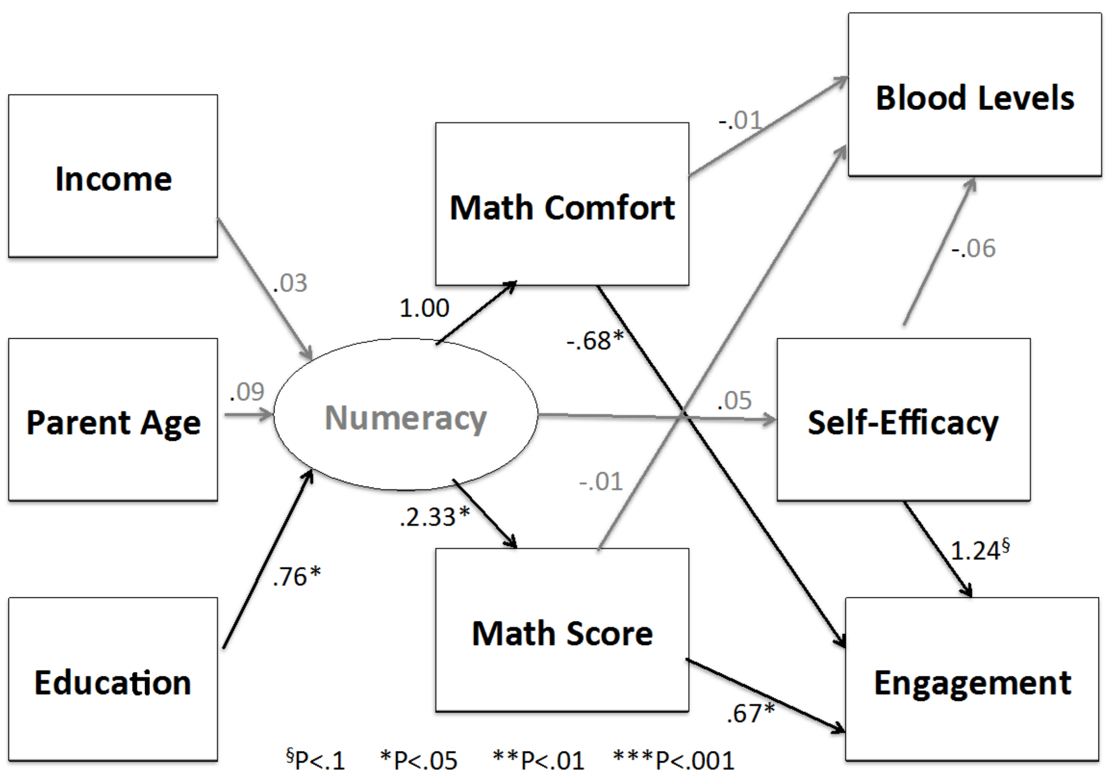
Model 2 tested whether income and education predicted blood levels or engagement independent of numeracy, which they do not (Figure 8). The pathway coefficient between education and engagement (r=1.53) greater than 1 indicates a strong influence of collinearity. The addition of two more paths into this model may have stretched the statistical power of the model, so relationships with P<.10 were considered significant when the path weight was substantial, as in the path between math score and engagement.

Figure 8. Pathway Model 2



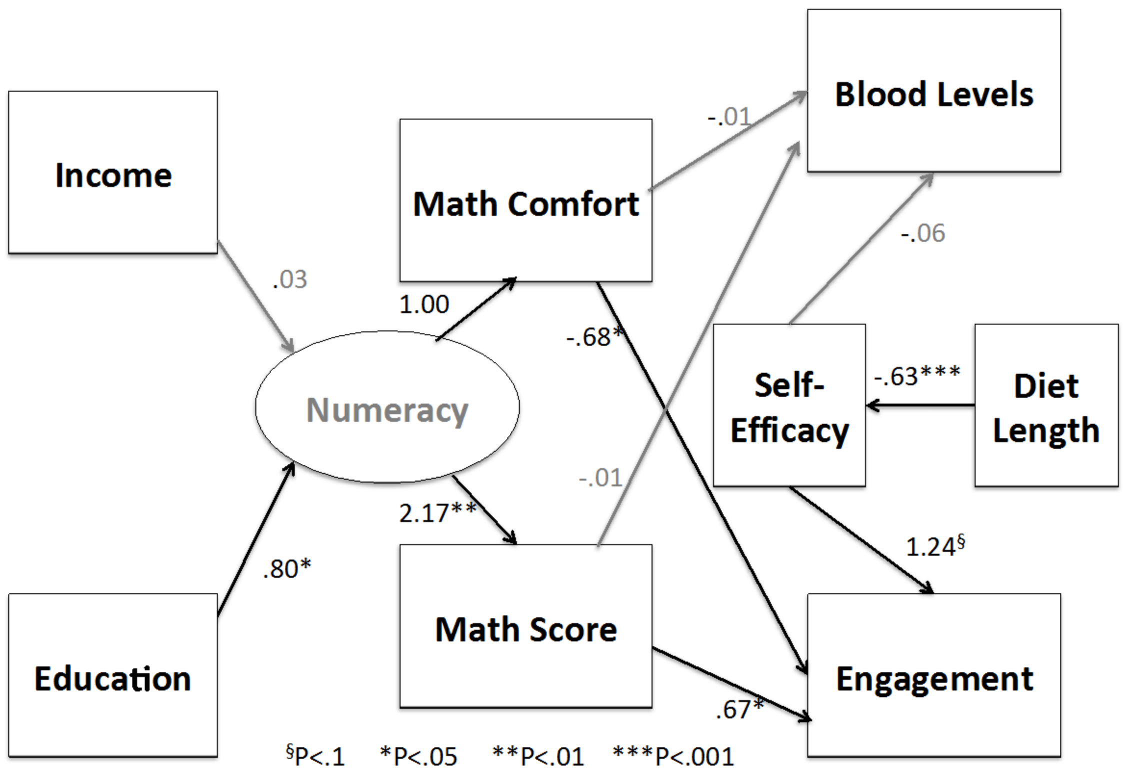
In Model 3 the non-significant pathways leading to the dependent variables were omitted, and a more direct pathway from numeracy to self-efficacy was tested. No relationship was apparent, and other pathway coefficients were unaffected by the change (Figure 9).

Figure 9. Pathway Model 3



To explore whether other measured variables might provide insight into self-efficacy, diet length was added to create Model 4 (Figure 10). The length of time the child had been on the special diet had a significant negative relationship with self-efficacy (r=-.62, P<.001).

Figure 10. Pathway Model 4



In summary, to what degree is parental numeracy related to achievement of treatment goals? Pathway analysis did not reflect a relationship between either cognitive or affective numeracy and health outcomes, as measured by the variables in this study. Results did not support the hypothesis that low cognitive numeracy acts as a direct barrier to diet management, or the prediction that self-efficacy would mediate the relationship between numeracy and both engagement in disease management and health outcome.

Affective numeracy was not associated with health outcome indicators; however factor analysis indicated it accounts for 25% of the variation in the variable "numeracy" which combines the cognitive and affective components. The null hypothesis that parental cognitive and affective numeracy has no effect on self-efficacy or health outcomes cannot be rejected. However, the same cannot be said for the relationship between numeracy and engagement. In pathway analysis, math scores were positively related to engagement, and math comfort was negatively related to engagement. In addition, the study revealed a strong and significant negative relationship between length of time on the diet and self-efficacy.

Parent Comments

Although unsolicited, parents often made comments to the investigator on the topics related to numeracy or to the challenges of managing PKU or T1D. Several parents stated that they hadn't thought about numeracy before, but they could see how it would have an impact on a parent's ability to manage the diet. One parent stated she worked with numbers all the time, but found it confusing to work with the measurement system she had been given at the clinic, which was in milligrams of phe per 100 grams of food. Another family described this system as the best way to manage the PKU diet, as she had committed to memory the factor to be applied when measuring particular foods, which made counting the diet much easier. Some parents were adept at math themselves, but worried about their children who struggled with math in school, wondering how they will manage the diet when they are on their own. The mother of a girl with T1D commented that although her daughter's A1c levels were good, she was having a lot of fluctuations in blood glucose levels with the onset of puberty.

Some parents made verbal comments during interviews while completing the test instruments. While completing the self-efficacy instrument, one parent commented, "I try, but it doesn't seem to help - I can't understand why her level stays so high!" Other parents sited outside factors get in the way of good levels despite parent's efforts - such as exercise, hormonal changes in older children; or limited access to special foods needed for the diet (for PKU) due to expense or availability. While this study did not include a qualitative component, many parents were eager to share their experiences with managing PKU or T1D.

CHAPTER V

CONCLUSION, DISCUSSION AND RECOMMENDATIONS

Conclusion

To further our understanding of pathways between determinants of health and outcomes, this study examined numeracy as a mediator of health disparities. Numeracy was studied using a comprehensive view from the adult learning literature that included cognitive and functional aspects but also the affective aspects of engaging in the use of numbers (Ginsburg, 2006). Nutrition, an essential component of health with an immense numerical component, was the subject matter of this research.

The specific purpose of the study was to evaluate the relationship between parental numeracy and health outcomes of their children who require complex diets. Parents of children with PKU and T1D were the subjects of the research, as a math-intensive, complex diet is a primary treatment in both conditions, and difficulty with diet management is common (Cavanaugh et al., 2008; Hassan & Heptulla, 2010; MacDonald, 2000; Walter, 2002).

One hundred parents were recruited in clinic and community settings. Data collection instruments included a validated test of cognitive numeracy, a scale of parental self-efficacy for diabetes which was also adapted for PKU, and a questionnaire on attitudes toward math. The latter instrument was developed based on a similar instrument from the field of math education. Validity and internal reliability testing were implemented during the research project. Completed questionnaires and children's blood levels were obtained for 98 participants. The hypothesis was that children of parents with lower cognitive and affective numeracy would have poorer metabolic control, (higher blood levels) and that self-efficacy would mediate this relationship as well as numeracy and engagement in diet management. Structural equation modeling was used to analyze the data.

The sample was evenly divided between parents of children with T1D and those with PKU. Mean parents age was 37 years, and mean child age was 7.3 years for the entire sample. Children had been on a special diet for a mean of 5 years. Race was predominantly white. In parents' description of their community of residence, suburbs or outskirts were most common, big city was least common, and other responses were about equally divided among medium-sized city or town, small town, and farm or country. Mean years of education were 14.5 years, and median yearly income was $67,5000. Private insurance (55% of children) was more common than public (38%).

In the sample as a whole, mean score on the measure of cognitive math skill was the 95th percentile for age. Mean affective math score was 31 (range of possible scores 14 - 70), and mean self-efficacy score was 33 (possible range 8 to 40). Of blood level measurements requested by the child's clinic, a mean of 73% were completed. The average blood phenylalanine level of children with PKU was 5.3, and mean A1c level of children with T1D was 8.3.

Children with higher blood levels indicating poor control were those whose parents had lower income and lower self-efficacy. Highest blood levels were predicted by low cognitive math score or less education. Parents with less education and income were less comfortable with math, and parental self-efficacy was lower when children had been on the diet for a longer time. Higher blood levels were more likely when children resided in rural settings or had public insurance.

In pathway analysis, education was the overriding variable that determined relationships among other variables. When education was accounted for, numeracy was not related to blood levels as hypothesized, and self-efficacy did not impact this relationship. Based on this model, affective and cognitive numeracy had opposite effects on engagement, and parental self-efficacy was less when children had been on the diet longer. However, the data did not support the proposed model. Thus the model would need to be retested with changes in the variables or predicted pathways to attempt to describe the relationship between these factors and health outcomes.

Discussion

Numeracy is an important consideration in parents' management of PKU and T1D. Low cognitive math skills correlate with high levels of harmful metabolites. In pathway analysis, however, results did not identify numeracy as a significant factor in health outcomes, but the pathways did provide insight into other factors that impact health outcomes in children on complex diets.

Bivariate correlation confirmed many of the relationships that are consistent with known determinants of health (WHO Commission on Social Determinants of Health, 2013). Education is highly correlated with income and cognitive math scores. In addition, children of parents who have less income and lower self-efficacy are significantly more likely to have higher mean blood levels of potentially harmful metabolites. Parents with less education and lower cognitive math scores are those with children whose mean blood levels indicate poor metabolic control. Their self-efficacy is lower, and they are significantly less likely to engage in blood monitoring. Parents who are more comfortable with math are those with greater income, education, and cognitive math skills, but blood levels are unaffected.

However, these correlations do not fully explain or describe the network of relationships that are present in the situational and health environment of child on a complex diet. Structural equation models identify the salient factors in this situation and the pathways by which they influence health outcomes. These factors are examined below.

Education.

Of the exogenous variables, education has the greatest impact on numeracy. Thus although income is correlated with both aspects of numeracy, it is via education that this relationship occurs. Parent age is not related to the combined factor numeracy once education is accounted for. Education also predominates in the relationship between numeracy and metabolic control. In other words, when education is accounted for, numeracy is not significantly related to health outcome.

The SEM was surprising in that none of the factors seemed to impact blood levels, even when the data were adjusted to target levels above goal. The model does not negate the relationship between blood levels and income or numeracy, but it explains that these relationships are dependent upon education. Years of schooling appear to be a salient factor impacting health outcome via other variables in the model.

Numeracy.

Numeracy includes both cognitive and affective components, and factor analysis confirmed that numeracy is not fully described without including both aspects. Research on health-related numeracy has been limited to the cognitive component, but the affective aspect of this characteristic is an active part of an individual's use of numbers. The very high correlation between standardized math test scores and comfort with math was predictable. But factor analysis revealed that the two components are not the same; they overlap considerably to create the variable Numeracy.

In contrast to findings of correlation between lower cognitive numeracy and high blood levels, in path analysis the relationship between numeracy and blood levels was not apparent. It is unclear whether the inclusion of affective numeracy in this relationship changed the pathway weights, but more likely the relationship was not evident after education was accounted for. Results may have been different if the cognitive math skills measured on the math test only included skills needed to manage diet and insulin. A discussion of the use of the WRAT-4 for cognitive skill assessment in this study is addressed in Chapter 2 along with review of all instruments administered.

In the present evaluation, numeracy was affected by education but not income. The effect of numeracy was not via self-efficacy as predicted in the hypothesis. This may be due to limitations on the measure of self-efficacy, which were revealed in pathway analysis and are addressed in a subsequent section.

While cognitive and affective numeracy are overlapping aspects of the variable numeracy, they have separate influences in the case of engagement. In fact they have directly opposite effects, though with nearly identical strengths in the relationships. Thus, once math skill is accounted for, more discomfort or anxiety related to math is associated with greater engagement. Conversely, when the affective component of math has been taken into consideration, parents with greater skill at math are less engaged. A review of the meaning of engagement in this model will help make sense of these findings.

Engagement.

Health behavior was measured in this study via engagement in measuring blood levels as recommended by the child's clinic. The true health behavior of interest however was adherence to a specific diet required for optimal health outcome. Based on the literature, (Bekhof et al., 2003) (Freehauf, Van Hove, Gao, Bernstein, & Thomas, 2013) and the assumption that parents who were less engaged in obtaining blood levels would also be less involved in diet management, engagement in home monitoring of blood levels was used as a proxy for engagement in diet management. The SEM model used both the results of blood levels and the frequency of blood testing as outcome variables. As a result, the study did not truly measure other aspects of engagement in the management of T1D and PKU, such as diet planning, food preparation, label-reading, parenting to enforce diet compliance, dietary intake, calculation or administration of insulin. By substituting engagement in blood monitoring, the causal link to numeracy and to some extent self-efficacy was more obscure, which is a weakness of this study.

Nonetheless, frequency of blood monitoring provided a window into whether parents are tracking this indicator of health outcome, and what factors are related to this behavior. Parents may decide to obtain blood levels for two main reasons: 1) to determine health status and alter treatment plan if needed, or 2) to be conscientious about following through on the clinic's instructions. Differing perspectives on these issues may explain differences between the numeracy variables and engagement.

Parents with a more negative affect concerning math monitored blood levels more frequently than those who described themselves as being more comfortable using numbers. Recognizing their difficulty with math, perhaps they were more unsure about the accuracy of their calculations related to diet or insulin, so chose to check levels more often. Personality or temperament may explain this relationship, as parents who worry about math may be more anxious in general. For example, some parents in the study checked blood level more often than recommended by the clinic (as high as 200% of recommendations). On the other hand, parents who are more relaxed about math may feel they have disease management in good control, and need less feedback from blood levels.

Parents with higher math scores were significantly more engaged in measuring blood levels. Education again explains this relationship. When education was added to the structural equation model (SEM 2), the strength of the relationship between math score and engagement dropped from R=.67 to R=.48 and significance also fell. The pathway weight between education and engagement of 1.53 indicates a high degree of collinearity in this relationship. Parents with more education may do more testing because they understand the disorder better and want to keep track of the child's progress. They understand the process of obtaining levels more clearly, or education may provide them with some other skill or characteristic that prompts them to check blood levels more often.

Self-Efficacy.

Self-efficacy is a popular variable in studies of behavior in health outcomes (Coleman, 2003; Grus et al., 2001; Mohebi, Azadbakht, Feizi, Sharifirad, & Kargar, 2013), and a key construct in the Health Belief Model(Becker, 1974). The lack of a relationship between either component of numeracy and self-efficacy was surprising, and did not support the hypothesis of this study. In medical conditions highly dependent on

mathematical calculations for successful treatment, ability and confidence related to math would seem to be directly connected to belief in one's ability to manage the treatment. The first clue to understanding this finding was the comments parents made during interviews. When comments were made while completing the self-efficacy scales, they usually reflected the parent's frustration with managing the child's condition.
This prompted a closer look at the self-efficacy scale.

Bandura distinguishes between self-efficacy and locus of control, which is concerned with beliefs about forces out of one's control (Bandura, 2006). An individual may believe they have a sense of efficacy in her/his own actions, but believe outcomes are determined by outside forces. A closer look at the items on the self-efficacy instrument (Appendices B and C) indicates that half of the questions refer to locus of control more than self-efficacy. For instance, "I take care of my child well when it comes to his/her PKU (or diabetes)" would measure self-efficacy, while other items refer to experiences with outcomes, such as "No matter how hard I try, taking care of my child's PKU (diabetes) doesn't turn out the way I like." Parents who have been unable to keep their child's blood levels in good control despite their best efforts may score low on the self-efficacy scale as a result.

Diet length.

A second clue to understanding self-efficacy scores came when length of diet was added to the SEM model. The number of years on the diet had a significant negative impact on self-efficacy score on the SEM (r=-.62, P=.000). While experienced parents might be expected to have greater self-efficacy about disease management, their beliefs in their abilities were lower than parents who had been managing the diet for shorter time. Thus it appears that self-efficacy feelings may change at different stages of disease management, and different child ages. Blood levels commonly worsen as children get older, even before adolescence (Chiang, Kirkman, Laffel, & Peters, 2014; Vockley et al., 2014). This trend can be attributed to physical factors such as hormonal changes, and behavioral changes as children become more independent and spend more time away from home. As outside factors arise that negatively impact metabolic control, parent's confidence in their ability to care for their child may dwindle. This is consistent with the observation that the self-efficacy scale also measures locus of control.

Findings related to theory.

The Health Belief Model (Figure 2) served as the theoretical model for this research, and the study findings are in keeping with the theoretical prediction that greater self-efficacy enhances the likelihood of action. In this study, this relationship was unveiled using SEM to control for the influence of education in this relationship. SEM findings acknowledge collinearity with other variables that influence this pathway.

For this study, the Health Belief Model (HBM) was amended to include a relationship between health action and health outcome (Figure 3), under the presumption that likelihood of action (engagement) results in better health. In most public health applications this is true: a health behavior such as getting a mammogram or giving up cigarettes improves the likelihood of better health. As discussed above, using frequency of blood levels as a proxy for diet adherence altered the meaning of the relationship between action and outcome; however, the addition of health outcome to the HBM was helpful in examining pathways leading to key health indicators.

Another addition to the Health Belief Model for this study was incorporating numeracy, with cognitive and affective numeracy as separate influences (Figure 3). This model correctly predicted the relationship between cognitive numeracy and likelihood of action, although the construct Benefits minus Barriers was not assessed. This relationship is only relevant if home monitoring is a valid proxy for diet management. A pathway from affective numeracy to self-efficacy was not supported by the outcome of this study. As described previously, an unexpected inverse relationship was apparent in this study between affective numeracy and likelihood of action. This outcome should be re-examined with dietary adherence action in place of participation in home blood monitoring as the action variable. Aside from this change in variables, the HBM along with additions unique to this study provided a valid framework for this analysis. The findings of this study however did not agree with the HBM, which theorizes that greater self-efficacy increases engagement in health behaviors.

Findings in light of related research.

Results of this study support related research and commentaries that acknowledge that the relationship between social characteristics, skills, beliefs, behaviors, and health is complex and not fully understood. As described elsewhere (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011), this study showed that many factors interact with numeracy to determine health outcomes in chronic health conditions.

Numeracy skills assessed in this sample were better than expected based on publications that state low numeracy is widespread in the U.S. (Goodman, 2013), but may be explained by the relatively high median household income of participants. The findings of this research were not as clear in measuring a relationship between numeracy and health outcomes as studies on other medical conditions. The strong association described by Apter et al may be due to the use of an asthma-specific instrument to measure numeracy (A. J. Apter, Cheng, J., Small, D., Bennett, I.M., Albert, X., Fein, D.G., George, M., Van Horne, S. , 2006), far different than the broader and more complex math skills measured by the WRAT-4.

Similar to this study, research by Pulgaron et al examined parental numeracy and glycemic control in children with T1D (Pulgaron et al., 2014). Similar to findings of this study, parental self-efficacy was not a mediator between numeracy and metabolic control, yet each of these factors independently was related to poor health outcome. This difference may be explained by the use of a diabetes-related numeracy measure versus the WRAT-4, and a somewhat younger age group (mean 6.8 years, range 3 to 9) which did not include children who had been on the diet as long as our sample. In addition, the differences between PKU and T1D may also be at play.

The findings of this study challenge the view that health literacy is a stronger predictor of health than age, race, income employment, or education (Al Sayah, Majumdar, Williams, Robertson, & Johnson, 2013). Findings also are in contrast with those of Marden et al who found that education explain the connection between numeracy and poor diabetes outcome (Marden et al., 2012). In this study of numeracy, education was the overriding factor in this network of relationships, and explained other pathways including health outcomes.

Health disparities and determinants of health.

What do the results of this study say about health disparities among children? In addition to the impact of education on health parameters depicted by the SEM, disparities in other determinants of health, peripheral to the model, were also related to health outcome. The type of community in which the child resided, as reported by the parent, was associated with a significant difference in mean blood levels indicative of metabolic control. Residents of large cities had the best blood levels, and those living in small towns, in the country, or on farms had poorest control. Further analysis would be useful to see whether education accounts for this difference in health outcome. Type of insurance was associated with health disparities when health outcome was evaluated in terms of levels above clinic goals. Children with public insurance were significantly more likely to have high blood levels. Further analysis may indicate whether this is a consequence of income or education. Data on children with no insurance was inconclusive due to small number of participants (n=3). Likewise no conclusions can be drawn on race, as the sample was predominantly (95%) white, as expected in view of the relatively lower incidence of PKU

(Vockley et al., 2014)and T1D (International Diabetes Federation, 2007)among non-whites. Household size and the number of adults in the home had no effect on health outcomes. In summary, while PKU and T1D seem to be specialized health conditions, children with these conditions are at risk for less desirable health outcomes due to the same characteristics that negatively impact health in the general population.

The research process.

Assumptions.

The pairing of PKU and TID in this study of numeracy did not cause inconsistencies in analysis or results. Minor differences were observed in demographic characteristics. If there were differences in data due to the fact all T1D patients were interviewed in one clinic while the PKU patients were served by 8 clinics over 5 states, it was not apparent. The study assumed that differences in medical providers would not impact results. While clinics varied in their expectations on frequency of blood levels, each clinic's standard was used as a basis for comparison in each participant. The one assumption that impacted the findings of the study was the aforementioned use of engagement in taking blood levels as a proxy for managing the diet in accordance with clinic recommendations. Another more subtle assumption was that excellent diet management by parents would result in excellent blood levels in their children, when in fact many other biological and environmental factors may come into play.

Recruitment.

While participants covered a wide range of income levels, families with lower income were likely underrepresented in the sample. For various reasons they are less likely to come to clinic appointments, and many obstacles keep them from participating at community events such as those at which parents of families with PKU were recruited.

Instruments and measurement tools.

Cognitive numeracy test

The WRAT-4 was chosen as it provided one of the few math tests standardized for adults of all ages. However, many of the items on the test are quite complex compared to the level of math skills needed for management of T1D or PKU. Complex math skills are not needed for managing either PKU or T1D, in fact, the tasks required are covered in Common Core curriculum at grade level 5 or 6. To separate the effect of education in general from numeracy skills related to disease management, further research could be conducted using a shorter math test that included only the math skills required for success. This would also address the culturally biased nature of the WRAT-4, as some parents schooled in non-traditional educational systems, such Old-Order Amish, are not exposed to the use of variables in equations even at the highest level of math education, at Grade 8.

Affective numeracy instrument.

This instrument demonstrated excellent internal reliability, and could be improved further by eliminating 2 or more items. A shortened version would eliminate questions on the participant's opinion of other people's preferences for using math, and those that alluded to math puzzles or games.

Self-efficacy scales.

The weakness of this scale has been discussed. In further research, the purpose of the instrument should be explored in comparison to the content of the questionnaire. The self-efficacy scale may be more appropriate for parents of younger children. Internal reliability of the instrument might be improved from acceptable to excellent with a more consistent theme among the test items.

Blood levels.

The validity of blood level data for children with the diagnosis of T1D was not questioned, as A1c levels came from one lab and home blood glucose levels provided extensive data from reliable devices. Phenylalanine levels may have been less valid, as data was not available on whether a child was ill at the time levels were taken. Parents are instructed to take a fasting level, either in the morning before eating, or 3 to 4 hours after a meal, but there may be variability in clinic guidelines, and compliance with the guidelines is not documented.

Analysis methods.

Structural equation modeling provided insights beyond correlation or linear regression. Further analysis of the data using a different model configuration may present additional findings. Additional variables might be considered, such as access to special low protein foods in the case of PKU, as it varies state-by-state. Addition of variables would require omission of other factors in analysis due to limitations of the model, depending on sample size. A revised analysis of the data should configure the model to eliminate self-efficacy or treat it as more peripheral factor.

Recommendations

How do the findings of this study add to our understanding of the pathway between numeracy and health outcomes? Does it inform clinical practice strategies that will enhance the success of all parents, especially those with the determinants of health that predict less desirable outcomes? Can our new understanding of numeracy and health acquired through the study of complex diets be applied to other settings where health and numeracy intersect? Lastly we will consider both direct implications of this research for PKU, T1D, and similar diet-dependent conditions, and consider whether this study can be applied to numeracy and health outcomes in other settings.

Disease Management Recommendations.

Numeracy skills are needed for complex diets, even if they account for a very small portion of the factors that determine health outcomes. In the clinical setting, patient or caretaker deficits in numeracy skills are not necessarily apparent, and may not be explored or recognized. Assessment of numeracy skills can guide patient education and training. The argument that patients and/or providers would be uncomfortable with evaluation of skills has not been supported in the literature. (White, Wolff, Cavanaugh, &

Rothman, 2010). In addition, math attitudes are a real part of numeracy and should be acknowledged when teaching parents.

Strategies have been explored to address the reality that limited math skills are not uncommon. Apter has recommended strategies to improve communication of numerical information (A. Apter et al., 2008). An extensive on-line toolkit for diabetes literacy and numeracy education, directed at providers and educators is available online at no cost (White et al., 2010). With this program as a reference, similar resources could be developed for parents of children with PKU, T1D, or other medical conditions requiring complex calculations. Tools may be needed to assess numeracy easily in a clinic setting, so teaching can be adapted to the parent's skills and comfort with math. To avoid the stress of a paper and pencil math test, an assessment tool resembling a video game could be created for use on hand-held electronic devices.

For those who are less skilled or more anxious about math, are there ways to get around math calculations? In diabetes, insulin pumps are reducing the number of parents who must manually calculate insulin doses, and apps are helping with carbohydrate counting. Similar technology is becoming more available for the PKU community, however it does not completely circumvent the use of numbers. Some level of understanding of math is needed to use such tools effectively, both to understand concepts and to implement the diet via purchasing, preparing, and measuring food. In PKU, an alternative is a simplified system for following the diet, in which only a few foods are measured or counted, but many very low protein fruits, vegetables, and modified grain products can be eaten freely.

This approach has been used successfully in the United Kingdom, but less so in the United States.

This study raises concerns about the trend of higher blood levels in late childhood and the implications for health outcomes. While often accepted as inevitable as children become more independent, spend more time away from parents, and assume some responsibilities for self-care, other factors may be at work, which research may identify. Meanwhile, anticipatory guidance for parents as their children reach this age may help them retain a sense of self-efficacy during this stage.

Knowing that numeracy is a nearly unavoidable aspect of food and nutrition, and recognizing the role of nutrition in health, public school curriculum could be developed that combines math and health issues including nutrition. Cross-curriculum content on food as related to numbers may be a way to help not only families with medical conditions such as PKU and T1D, but also others who seek to improve their diets. Food-related skills were eliminated from middle and high schools when computer courses replaced home economics in the 1990's, so today's parents may not have learned these skills at school. They may not have learned at home due to cultural trends that favor eating away from home. Application of curriculum on fractions, percentages, and measurement to food would build numeracy skills in this context. The current interest in food and cooking may drive this change. Students would be more adept at baseline food-related numeracy tasks, and have a foundation when the need for more complex food calculation arises.

Improving the research.

A weakness in this study was the lack of data about parents' application of numeracy. Additional research on this topic is recommended to include analysis of dietary intake. These data can be time-consuming to obtain, but in some cases it is already collected by the clinic. Research would also be improved by using a simpler instrument to evaluate cognitive math skills. This would enable a better assessment of the degree to which the use of numbers is an obstacle in diet management. While disease-specific tests are often used in health numeracy research, this approach measures whether people who have developed the skills to manage the disease do in fact implement that knowledge. The broader question is whether parents with weaker math skills from the beginning are at higher risk of being unable to keep the child's condition in good control. Then interventions and teaching strategies can be designed that target those with fewer skills to enhance their likelihood of success.

A revision of the self-efficacy survey used in this study is also recommended. Questions could be separated into those that assess one's ability to manage the disorder from those that reflect concern over whether outside factors will undermine even the best parent management. Each of these sets of parental attitudes deserves study. To continue to research the significance of this concept on health outcome pathways, new scales are needed that are applicable to parents of children at different ages.

Practically speaking, recruitment would have been smoother and more inclusive if a gift card had been offered instead of a lunch kit gift from the beginning of the study. The lunch kit did not seem to adequately compensate families for their time following a busy clinic visit, limiting the participating parents to those who appreciated the importance of research, typically those with more education. Likewise, to obtain a socioeconomically diverse sample, the research process should anticipate obstacles that may prevent families with fewer resources from participating, such as the cost of parking or assistance with care of other children present at the time of data collection.

Recommendations for further research.

This study of numeracy in complex diets has provided useful insights on relationships among factors that impact health outcomes. It adds to the literature on numeracy and diet management of all diets that require math, but particularly of PKU, for which the topic has not been explored. It raises new questions about the older school-age or preadolescent child on a chronic and complex diet. Research is needed to evaluate whether interventions during this period can prevent the trend of worsening control.

If the study population were widened beyond PKU and T1D to other diet and nutrition issues, it could include a more diverse array of race and income levels and assess the impact of those variables on health outcome. In view of the findings that numeracy explained differences in medication management of HIV that had previously been attributed to race or gender (Waldrop-Valverde et al., 2010), other situations may exist in which numeracy is an unrecognized factor on causal pathways. Additional research on numeracy as a determinant of health may reveal these relationships.

A unique contribution of this study to the literature is its recognition of the affective component of numeracy. Further research could reveal more about how the relationship between these two aspects of numeracy impact the use of numbers in other health-related applications. This has particular application to the study of numeracy in health risk assessment when emotions are already a known factor.

While developments in technology will change the way numbers are used in diet planning, research will be needed to address the ways in which technology does and does not address limited numeracy. Studies of utilization trends will be needed to determine ways to make such aids accessible to those with low incomes and understandable by those with less education. This research has confirmed that education in particular is a key factor in parents' ability to manage their children's complex diets for optimal health outcomes.

REFERENCES

Abrams, M. A., Klass, P., & Dreyer, B. P. (2009). Health literacy and children: introduction. *Pediatrics, 124 Suppl 3*(Suppl 3), S262-264. doi: 10.1542/peds.2009-1162A

Ad Hoc Committee on Health Literacy. (1999). Health Literacy: report of the council on scientific affairs. *Journal of the American Medical Association, 281*, 552-557.

Ad Hoc Committee on Health Literacy for the Council on Scientific, A., & American Medical, A. (1999). Health literacy: Report of the council on scientific affairs. *JAMA, 281*(6), 552-557. doi: 10.1001/jama.281.6.552

Aggarwal, A., Speckman, J. L., Paasche-Orlow, M. K., Roloff, K. S., & Battaglia, T. A. (2007). The Role of Numeracy on Cancer Screening Among Urban Women. *American Journal of Health Behavior, 31*(1), S57-S68.

Aiken, L. (1974). Two scales of attitude toward mathematics. *Journal for Research in Mathematics Education, 5*, 67-71.

Al Sayah, F., Majumdar, S., Williams, B., Robertson, S., & Johnson, J. (2013). Health Literacy and Health Outcomes in Diabetes: A Systematic Review. *Journal of General Internal Medicine, 28*(3), 444-452. doi: 10.1007/s11606-012-2241-z

Al Sayah, F., Williams, B., & Johnson, J. A. (2013). Measuring Health Literacy in Individuals With Diabetes: A Systematic Review and Evaluation of Available

Measures. *Health Education & Behavior, 40*(1), 42-55. doi: 10.1177/1090198111436341

American Diabetes Association. (2003). Evidence-Based Nutrition Principles and Recommendations for the Treatment and Prevention of Diabetes and Related Complications. *Diabetes Care, 26*(suppl 1), s51-s61. doi: 10.2337/diacare.26.2007.S51

American Diabetes Association. (2006). Your A1C Results: What do they mean? *Clinical Diabetes, 24*(19). doi: doi: 10.2337/diaclin.24.1.9

American Diabetes Association. (2013). Carbohydrate Counting. Retrieved 11/22/2013, from http://www.diabetes.org/food-and-fitness/food/planning-meals/carb-counting/

American Heart Association. (2010). Fats and Oils: AHA Recommendations. Retrieved 3/4/2014, from http://www.heart.org/HEARTORG/GettingHealthy/FatsAndOils/Fats101/Fats-and-Oils-AHA-Recommendation_UCM_316375_Article.jsp

American Institute for Research. (2006). A Review of the Literature in Adult Numeracy: Research and Conceptual Issues. Washington, D.C.: American Institutes for Research.

Ancker, J. S., & Kaufman, D. (2007). Rethinking Health Numeracy: A Multidisciplinary Literature Review. *Journal of the American Medical Informatics Association, 14*(6), 713-721. doi: 10.1197/jamia.M2464

Apter, A., Paasche-Orlow, M., Remillard, J., Bennett, I., Ben-Joseph, E., Batista, R., . . . Rudd, R. (2008). Numeracy and Communication with Patients: They Are

Counting on Us. *Journal of General Internal Medicine, 23*(12), 2117-2124. doi: 10.1007/s11606-008-0803-x

Apter, A. J., Cheng, J., Small, D., Bennett, I.M., Albert, X., Fein, D.G., George, M., Van Horne, S. . (2006). Asthma Numeracy Skill and Health Literacy. *Journal of Asthma, 43*(9), 705-710. doi: 10.1080/02770900600925585

Apter, A. J., Wang, X., Bogen, D., Bennett, I. M., Jennings, R. M., Garcia, L., . . . Ten Have, T. (2009). Linking numeracy and asthma-related quality of life. *Patient Education and Counseling, 75*(3), 386-391. doi: http://dx.doi.org/10.1016/j.pec.2009.01.003

Ashcraft, M. H. M., A.M. (2009). Mathematics Anxiety and the Affective Drop in Performance. *Journal of Psychoeducational Assessment, 27*, 197-205. doi: 10.1177/0734282908330580

Asher, H. B. (1976). *Causal Modeling*. Beverly Hills, CA: Sage Publications.

Bai, H., Wang, W.P., Frey, M. (2008). Measuring Mathematics Anxiety: Psychometric Analysis of a Bidemensional Affective Scale. *J Instruct Psych, 36*(3), 185-193.

Baker, D. W. (2006). The meaning and the measure of health literacy. *Journal of General Internal Medicine, 21*(8), 878-883. doi: 10.1111/j.1525-1497.2006.00540.x

Baker, D. W., Williams, M. V., Parker, R. M., Gazmararian, J. A., & Nurss, J. (1999). Development of a brief test to measure functional health literacy. *Patient Educ Couns, 38*(1), 33-42.

Bandura, A. (1977). Self-efficacy: toward a unifying theory of behavioral change. *Psychol Rev, 84*(2), 191-215.

Bandura, A. (1982). Self-efficacy mechanism in human agency. *American Psychologist, 37*(2), 122-147. doi: 10.1037/0003-066x.37.2.122

Bandura, A. (2006). Guide for Constucting Self-Efficacy Scales. In F. Pajares, Urdan, T. (Ed.), *Self-Efficacy Beliefs of Adolescents* (pp. 307-337): Information Age Publishing, Inc.

Bann, C. M., McCormack, L. A., Berkman, N. D., & Squiers, L. B. (2012). The Health Literacy Skills Instrument: A 10-Item Short Form. *Journal of Health Communication, 17*, 191-202. doi: 10.1080/10810730.2012.718042

Barclay, T. R., Hinkin, C. H., Castellon, S. A., Mason, K. I., Reinhard, M. J., Marion, S. D., . . . Durvasula, R. S. (2007). Age-associated predictors of medication adherence in HIV-positive adults: health beliefs, self-efficacy, and neurocognitive status. *Health Psychol, 26*(1), 40-49. doi: 10.1037/0278-6133.26.1.40

Baur, C. (2010). New directions in research on public health and health literacy. *J Health Commun, 15 Suppl 2*, 42-50. doi: 10.1080/10810730.2010.499989

Becker, M. H. (1974). The Health Belief Model and Personal Health Behavior. *Health Education Monographs, 2*, 324-473.

Bekhof, J., Spronsen, F., Crone, M., Rijn, M., Oudshoorn, C. M., & Verkerk, P. (2003). Influence of knowledge of the disease on metabolic control in phenylketonuria. *European Journal of Pediatrics, 162*(6), 440-442. doi: 10.1007/s00431-003-1197-8

Berkman, N., Davis, T., McCormack, L. (2010). Health Literacy: What Is It? *Journal of Health Communication, 15*(Supplement), 9-19.

Berkman N.D., D. T. C. M. L. (2010). Health literacy: what is it? *Journal of Health Communication, 15*, 9-19.

Berkman, N. D., Dewalt, D.A., Pignone, M.P., et al. (2004). Literacy and health outcomes *Evid Rep Technol Assess* (Vol. 87, pp. 1-8).

Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., & Crotty, K. (2011). Low Health Literacy and Health Outcomes: An Updated Systematic Review. *Annals of Internal Medicine, 155*(2), 97-W41.

Berkman, N. D., Sheridan, S.L., Donahue, K.E., Halpern, D.J., Viera, A., Crotty, K., Holland,A., Brasure, M., Lohr, K.N., Harden, E., Tant, E., Wallace, I., Viswanathan, M. (2011). Health Literacty Interventions and Outcomes: An Updated Systematic Review: Executive Summary No. 199 *Evidence Report: Technology Assessment*. Rockville, MD: Agency for Healthcare Research and Quality.

Bowen, M. E., Cavanaugh, K. L., Wolff, K., Davis, D., Gregory, B., & Rothman, R. L. (2013). Numeracy and Dietary Intake in Patients With Type 2 Diabetes. *The Diabetes Educator, 39*(2), 240-247. doi: 10.1177/0145721713475841

Bryanton, J., Gagnon, A.J., Hatem, M., Johnston, C. (2008). Predictors of Early Parenting Self-efficacy. *Nursing Research, 57*(4), 252-259.

Cambrooke Foods. (2010). DietWell for PKU App. Retrieved 3/10/14, from http://www.cambrookefoods.com/dietwell/app.php

Carbone, E. T., & Zoellner, J. M. (2012). Nutrition and Health Literacy: A Systematic Review to Inform Nutrition Research and Practice. *Journal of the Academy of Nutrition & Dietetics, 112*(2), 254-265. doi: 10.1016/j.jada.2011.08.042

Carmona, R. (2003). Health Literacy in America: The Role of Health Care Professionals. *American Medical Association House of Delegates Meeting.* Retrieved 1/11/2014, from http://www.surgeongeneral.gov/news/speeches/ama061403.html

CASAS. (2013). Comprehensive Adult Student Assessment Systems. 2013, from https://www.casas.org/

Cavanaugh, K., Huizinga, M. M., Wallston, K. A., Gebretsadik, T., Shintani, A., Davis, D., . . . Rothman, R. L. (2008). Association of numeracy and diabetes control. *Ann Intern Med, 148*(10), 737-746.

Cavanaugh, K., Wallston, K. A., Gebretsadik, T., Shintani, A., Huizinga, M. M., Davis, D., . . . Rothman, R. L. (2009). Addressing literacy and numeracy to improve diabetes care: two randomized controlled trials. *Diabetes Care, 32*(12), 2149-2155. doi: 10.2337/dc09-0563

Centers for Disease Control and Prevention. (2013). Gateway to Health Communication and Social Marketing Practice. Retrieved 12/3/13, from http://www.cdc.gov/healthcommunication/

Chamberlin, S. A. (2010). A review of instruments created to assess affect in mathematics. *Journal of Mathematics Education, 3*(1), 167-182.

Chiang, J. L., Kirkman, M. S., Laffel, L. M. B., & Peters, A. L. (2014). Type 1 Diabetes Through the Life Span: A Position Statement of the American Diabetes Association. *Diabetes Care, 37*(7), 2034-2054. doi: 10.2337/dc14-1140

Coleman, P. R., & Karraker, K. H. (2003). Maternal Self-Efficacy Beliefs, Competence in Parenting, and Toddlers: Behavior and Developmental Status. *Infant Mental Health Journal, 24*(2), 126-148. doi: 10.1002/imhj.10048

Common Core State Standards Initiative. (2012). Standards for Mathematical Practice. from http://www.corestandards.org/Math

Cotugno, G., Nicolò, R., Cappelletti, S., Goffredo, B. M., Vici, C. D., & Di Ciommo, V. (2011). Adherence to diet and quality of life in patients with phenylketonuria. *Acta Paediatrica, 100*(8), 1144-1149. doi: 10.1111/j.1651-2227.2011.02227.x

Craig, M. E., Hattersley, A., & Donaghue, K. C. (2009). Definition, epidemiology and classification of diabetes in children and adolescents. *Pediatric Diabetes, 10*, 3-12. doi: 10.1111/j.1399-5448.2009.00568.x

Cristine M. Trahms Program for Phenylketonuria. (2008). PKU Education Curriculum. Retrieved January 28, 2013, from http://depts.washington.edu/pku/management/index.html

Crone, M. R., van Spronsen, F.J., Oudshoorn, K., Bekhof, J., van Rijn, G., Verderk, P.H. (2005). Behavioural factors related to metabolic control in patients with phenylketonuria. *J Inherit Metab Dis, 28*(5), 627-637. doi: 10.1007/s10545-005-0014-0

CTB Research. (2013). Tests of Adult Education. Retrieved 11/13/2013, from http://www.ctb.com/ctb.com/control/productFamilyViewAction?productFamilyId=608&p=products

Cullen, K. W., Anderson, B. J., McKay, S., & Watson, K. (2007). Psychometric properties of questionnaires measuring associations between behavioral factors and diabetes care for youth with type 2 diabetes. *Pediatric Diabetes, 8*(1), 21-27. doi: 10.1111/j.1399-5448.2006.00222.x

Davis, T. C., Long, S. W., Jackson, R. H., Mayeaux, E. J., George, R. B., Murphy, P. W., & Crouch, M. A. (1993). Rapid estimate of adult literacy in medicine: a shortened screening instrument. *Fam Med, 25*(6), 391-395.

Dewalt, D. A., Berkman, N. D., Sheridan, S., Lohr, K. N., & Pignone, M. P. (2004). Literacy and health outcomes: a systematic review of the literature. *Journal of General Internal Medicine, 19*(12), 1228-1239. doi: 10.1111/j.1525-1497.2004.40153.x

DeWalt, D. H., A. (2009). Health literacy and child health outcomes: a systemic review of the literature. *Pediatrics, 124*(Suppl), S265-S274. doi: 10.1542/peds.2009-1162B

Eccles, J. S. J., J.E. (1986). Social forces shape math attitudes and performance. *Signs, 11*(2), 367-380.

Estrada, C. A., Martin-Hryniewicz, M., Peek, B. T., Collins, C., & Byrd, J. C. (2004). Literacy and numeracy skills and anticoagulation control. *Am J Med Sci, 328*(2), 88-93.

Excellence Gateway. (2013). Adult Numeracy Core Curriculum. Retrieved 11/14/13, from http://www.excellencegateway.org.uk/node/1514

Fagerlin, A., Zikmund-Fisher, B. J., Ubel, P. A., Jankovic, A., Derry, H. A., & Smith, D. M. (2007). Measuring Numeracy without a Math Test: Development of the Subjective Numeracy Scale. *Medical Decision Making, 27*(5), 672-680. doi: 10.1177/0272989x07304449

Fennema, E. S., J.A. (1976). Fennema-Sherman Mathematics Attitude Scales: Instruments Designed to Measure Attitudes toward the Learning of Mathematics by Females and Males. *Journal for Research in Mathematics Education, 7*(5), 324-326.

Fisch, R. O. (2000). Comments on diet and compliance in phenylketonuria. *Eur J Pediatr, 159* ([Suppl 2]), S142-S144.

Freehauf, C., Van Hove, J. L. K., Gao, D., Bernstein, L., & Thomas, J. A. (2013). Impact of geographic access to care on compliance and metabolic control in phenylketonuria. *Molecular Genetics and Metabolism, 108*(1), 13-17. doi: http://dx.doi.org/10.1016/j.ymgme.2012.09.026

Gazmararian, J. A., Curran, J. W., Parker, R. M., Bernhardt, J. M., & DeBuono, B. A. (2005). Public health literacy in America: An ethical imperative. *American Journal of Preventive Medicine, 28*(3), 317-322. doi: http://dx.doi.org/10.1016/j.amepre.2004.11.004

Ginsburg, L., Manly, M., Schmitt, M.J. (2006). The Concept of Numeracy *NCSALL Occasional Papers*. Cambridge, MA: National Center for the Study of Adult Learning and Literacy.

Given, J. E., O'Kane, M. J., Bunting, B. P., & Coates, V. E. (2013). Comparing patient-generated blood glucose diary records with meter memory in diabetes: a systematic review. *Diabetic Medicine, 30*(8), 901-913. doi: 10.1111/dme.12130

Glassman, P. (2013). Health Literacy. Retrieved 3/1/14, from http://nnlm.gov/outreach/consumer/hlthlit.html#A4

Golbeck, A. L., Ahlers-Schmidt, C. R., Paschal, A. M., & Dismuke, S. E. (2005). A Definition and Operational Framework for Health Numeracy, Editorial. *American Journal of Preventive Medicine,* pp. 375-376. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=aph&AN=19008406&site=ehost-live

Goodman, M., Finnegan, R., Mohadjer, L., Krenzke, T., and Hogan, J. (2013). Literacy, Numeracy, and Problem Solving in Technology-Rich Environments Among U.S.Adults: Results from the Program for the International Assessment of Adult Competencies 2012: First Look. Washington, D.C.: U.S. Department of Education.

Green, J. K., Rothman, R. L., & Cavanaugh, K. L. (2012). Patient–provider communication in patients with diabetes and depressive symptoms. *Diabetes Research and Clinical Practice, 95*(1), e10-e13. doi: http://dx.doi.org/10.1016/j.diabres.2011.09.024

Grey, M., Boland, E. A., Yu, C., Sullivan-Bolyai, S., & Tamborlane, W. V. (1998). Personal and Family Factors Associated With Quality of Life in Adolescents With Diabetes. *Diabetes Care, 21*(6), 909-914. doi: 10.2337/diacare.21.6.909

Grossman, H. Y., Brink, S., & Hauser, S. T. (1987). Self-efficacy in adolescent girls and boys with insulin-dependent diabetes mellitus. *Diabetes Care, 10*(3), 324-329.

Grus, C. L., Lopez-Hernandez, C., Delamater, A., Appelgate, B., Brito, A., Wurm, G., & Wanner, A. (2001). Parental self-efficacy and morbidity in pediatric asthma. *J Asthma, 38*(1), 99-106.

Hassan, K., & Heptulla, R. A. (2010). Glycemic control in pediatric type 1 diabetes: role of caregiver literacy. *Pediatrics, 125*(5), e1104-1108. doi: 10.1542/peds.2009-1486

Health Resources and Service Administration. (2012). Health Literacy. Retrieved 12/3/13, from http://www.hrsa.gov/publichealth/healthliteracy/

Huizinga, M. M., Beech, B. M., Cavanaugh, K. L., Elasy, T. A., & Rothman, R. L. (2008). Low Numeracy Skills Are Associated With Higher BMI. *Obesity, 16*(8), 1966-1968. doi: 10.1038/oby.2008.294

Huizinga, M. M., Carlisle, A. J., Cavanaugh, K. L., Davis, D. L., Gregory, R. P., Schlundt, D. G., & Rothman, R. L. (2009). Literacy, Numeracy, and Portion-Size Estimation Skills. *American Journal of Preventive Medicine, 36*(4), 324-328. doi: 10.1016/j.amepre.2008.11.012

Huizinga, M. M., Elasy, T. A., Wallston, K. A., Cavanaugh, K. L., Davis, D., Gregory, R. P., . . . Rothman, R. L. (2008). Development and validation of the Diabetes Numeracy Test (DNT). *BMC Health Services Research, 8*, 1-8. doi: 10.1186/1472-6963-8-96

Huizinga, M. M., Pont, S., Rothman, R. L., Perrin, E., Sanders, L., & Beech, B. (2008). ABC's and 123's: Parental Literacy, Numeracy, and Childhood Obesity. *Obes Manag, 4*(3), 98-103. doi: 10.1089/obe.2008.0163

Iannotti, R. J., Schneider, S., Nansel, T.R., Haynie, D.L., Plotnick, L.P., Clark, L.M., Sobel, D.O., Simons-Morton, B. (2005). Self-efficacy, outcome expectations,. *J Dev Behav Pediatr, 27*, 98-105.

Ievers-Landis, C. E., Hoff, A.L., Brez, C., Cancilliere, M.K., McConnell, J., Kerr, D. (2005). Situational analysis of dietary challenges of the treatment regimen for children and adolescents with phenylketonuria and their primary caregivers. *Journal of Developmental and Behavioral Pediatrics, 26*(3), 186-193.

Institute of Medicine. (2004). *Health Literacy: A Prescription to end confusion*. National Academy of Sciences Retrieved from http://www.iom.edu/~/media/Files/Report%20Files/2004/Health-Literacy-A-Prescription-to-End-Confusion/healthliteracyfinal.pdf.

International Diabetes Federation. (2007). Diabetes in children: epidemiology. *Pediatric Diabetes, 8*, 10-18. doi: 10.1111/j.1399-5448.2007.00302.x

International Diabetes Federation. (2014). Childhood Diabetes Education Resources in English. Retrieved 3/10/14, from http://www.idf.org/lifeforachild/diabetes-education-resources/english

Jay, M., Adams, J., Gillespie, C., et al. (2009). A randomized trial of a brief multimedia intervention to improve comprehension of food labels. *Prev Med, 48*(1), 25-31.

Joram, E., Roberts-Dobie, S., Mattison, S. J., Devlin, M., Herbrandson, K., Hansen, K., & Eslinger, D. (2012). The Numeracy Demands of Health Education Information: An Examination of Numerical Concepts in Written Diabetes Materials. *Health Communication, 27*(4), 344-355. doi: 10.1080/10410236.2011.586987

Kelo, M., Martikainen, M., & Eriksson, E. (2011). Self-care of school-age children with diabetes: an integrative review. *Journal of Advanced Nursing, 67*(10), 2096-2108. doi: 10.1111/j.1365-2648.2011.05682.x

Kerr, D. (2010). Poor numeracy: the elephant in the diabetes technology room. *J Diabetes Sci Technol, 4*(6), 1284-1287.

Kirsch, I. S., Jungeblue, A., Jenkins, L., Kolstad, A. (1993). *Adult Literacy in America: A First Look at the Results of the National Adult Literacy Survey (NALS)*.

Washington, DC: National Center for Education Statistics, U.S. Department of Education.

Kumar, D., Sanders, L., Perrin, E. M., Lokker, N., Patterson, B., Gunn, V., . . . Rothman, R. L. (2010). Parental Understanding of Infant Health Information: Health Literacy, Numeracy, and the Parental Health Literacy Activities Test (PHLAT). *Academic Pediatrics, 10*(5), 309-316. doi: http://dx.doi.org/10.1016/j.acap.2010.06.007

Kutner, M., Greeberg, E., Jin, Y., Boyle, B., Hsu, Y., Dunleavy., E. (2007). *Literacy in Everyday Life: Results from the 2003 National Assessment of Adult Literacy*. Washington, D.C.: National Center for Education Statistics.

Lawshe, C. H. (1975). A Quantitative Apporach to Content Validity. *Personnel Psychology, 28*, 563-575.

Leonard, B. J., Skay, C. L., & Rheinberger, M. M. (1998). Self-management development in children and adolescents with diabetes: The role of maternal self-efficacy and conflict. *Journal of Pediatric Nursing, 13*(4), 224-233. doi: http://dx.doi.org/10.1016/S0882-5963(98)80049-3

Lipkus, I. M., Samsa, G., & Rimer, B. K. (2001). General Performance on a Numeracy Scale among Highly Educated Samples. *Medical Decision Making, 21*(1), 37-44. doi: 10.1177/0272989x0102100105

Lyons, I. M., & Beilock, S. L. (2012). When Math Hurts: Math Anxiety Predicts Pain Network Activation in Anticipation of Doing Math. *PLoS ONE, 7*(10), 1-6. doi: 10.1371/journal.pone.0048076

MacDonald, A. (2000). Diet and compliance in phenylketonuria. *Eur J Pediatr, 159 Suppl 2*, S136-141.

MacDonald, A., Davies, P., Daly, A., Hopkins, V., Hall, S. K., Asplin, D., . . . Chakrapani, A. (2008). Does maternal knowledge and parent education affect blood phenylalanine control in phenylketonuria? *Journal of Human Nutrition & Dietetics, 21*(4), 351-358.

MacDonald, A., Gokmen-Ozel, H., van Rijn, M., & Burgard, P. (2010). The reality of dietary compliance in the management of phenylketonuria. *J Inherit Metab Dis, 33*(6), 665-670. doi: 10.1007/s10545-010-9073-y

Mackner, L., McGrath, A., & Stark, L. (2001). Dietary recommendations to prevent and manage chronic pediatric health conditions: adherence, intervention, and future directions. *J Dev Behav Pediatr, 22*, 130-143.

Maloney, E. A., Ansari, D., & Fugelsang, J. A. (2011). The effect of mathematics anxiety on the processing of numerical magnitude. *Q J Exp Psychol (Hove), 64*(1), 10-16. doi: 10.1080/17470218.2010.533278

Maloney, E. A., & Beilock, S. L. (2012). Math anxiety: who has it, why it develops, and how to guard against it. *Trends in Cognitive Sciences,* pp. 404-406. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=aph&AN=77967058&site=ehost-live

Maloney, E. A., Risko, E.F., Ansari, D., Fugelsang, J. (2010). Mathematics anxiety affects counting but not subitizing during visual enumeration. *Cognition, 114*, 293-297. doi: 10.1016/j.cognition.2009.09.013

Marchante, A. N., Pulgaron, E.R., Dalgre, A., Patino-Fernandez, A.M., Sanchez, J., Sanders, L.M., Delamater, A.M. (2013). Measurement of Parental Self-Efficacy for Diabetes Management in Young Children. *Children's Health Care*. doi: 10.1080/02739615.2014.849957

Marden, S., Thomas, P. W., Sheppard, Z. A., Knott, J., Lueddeke, J., & Kerr, D. (2012). Poor numeracy skills are associated with glycaemic control in Type 1 diabetes. *Diabetic Medicine, 29*(5), 662-669. doi: 10.1111/j.1464-5491.2011.03466.x

Marvicsin, D. (2008). School-Age Children with Diabetes: Role of Maternal Self-Efficacy, Environment, and Management Behaviors. *The Diabetes Educator, 34*(3), 477-483.

McCormack, L., Bann, C., Squiers,L., Berkman, N.S., Squire, C., Schillinger, D., Hibbard, J. (2010). Measuring health literacy: a pilot of a new skills-based instrument. *Journal of Health Communication, 15*(Suppl. 2), 51-71.

McLeod, D. B. (1994). Research on Affect and Mathematics Learning in the JRME: 1970 to the Present. *Journal for Research in Mathematics Education, 25*(6), 637-647.

McNaughton, C. D., Collins, S.P., Kripalani, S., Rothman, R., Self, W.H., Jenkins, C., Miller, K., Arbogast, P., Dittus, R.S., Storrow, A.B. (2013). Low numeracy is associated with increased odds of 30-day emergency department or hospital recitivism for patients with acute heart failure. *Circ Heart Fail, 6*(1).

McNaughton, C. D., Rothman, R., Marcovitz, D.E., Storrow, A.B. (2011). Short, subjective measures of numeracy and general health literacy in an adult emergency department. *Acad Emerg Med, 18*, 1148-1155.

Merkel, R. M., Wright, T. (2012). Parental Self-Efficacy and Online Support among Parents of Children Diagnoses with Type 1 Diabetes Mellitus. *Pediatric Nursing, 38*(6), 303-308.

Ministry of Education. (1959). A report of the Central Advisory Committee for Education (England). London.

Miser, W. F., Jeppesen, K. M., Wallace, L. S. (2013). Clinical utility of a brief screen for health literacy and numeracy among adults with diabetes mellitus. *Family medicine, 45*(6), 417-423.

Mohebi, S., Azadbakht, L., Feizi, A., Sharifirad, G., & Kargar, M. (2013). Review the key role of self-efficacy in diabetes care. *J Educ Health Promot, 2*, 36. doi: 10.4103/2277-9531.115827

Montori, V., & Rothman, R. (2005). Weakness in numbers. *Journal of General Internal Medicine, 20*(11), 1071-1072. doi: 10.1111/j.1525-1497.2005.051498.x

Mulvaney, S. A., Lilley, J. S., Cavanaugh, K. L., Pittel, E. J., & Rothman, R. L. (2013). Validation of the diabetes numeracy test with adolescents with type 1 diabetes. *J Health Commun, 18*(7), 795-804. doi: 10.1080/10810730.2012.757394

National Center for Educational Statistics. (2003). 2003 National Assessment of Adult Literacy: U.S. Department of Education.

National Institutes of Health. (2000). Phenylketonuria (PKU): Screening and Management. *NIH Consensus Statement* (pp. 1-33). Kensington, MD: National Institute of Health.

National PKU Alliance. (2013). *My PKU Binder*   Retrieved from http://npkua.org/Education/MyPKUBinder.aspx

Nelson, J. C., Schwartzberg, J. G., & Vergara, K. C. (2005). The public's and the patient's right to know: AMA commentary on "Public Health Literacy in America: An ethical imperative". *American Journal of Preventive Medicine, 28*(3), 325-326. doi: http://dx.doi.org/10.1016/j.amepre.2004.12.011

Nelson W.I., M., R. P., Han, P. K. (2013). Exploring objective and subjective numeracy at a population level: findings from the 2007 Health Information National Trends Survey (HINTS). *Journal of Health Communication, 18*(2), 192-205.

Nutbeam, D. (2000). Health literacy as a public health goal: A challenge for contemporary health education and communicatin strategies into the 21st century. *Health Promotion International, 15*, 259-267.

Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science & Medicine, 67*(12), 2072-2078. doi: http://dx.doi.org/10.1016/j.socscimed.2008.09.050

Organisation for Economic Cooperation and Development. (2012). *Literacy, Numeracy and Problem Solving in Technology-Rich Environments: Framework for the OECD Survey of Adult Skills*: OECD Publishing.

Osborn, C. Y., Cavanaugh, K., Wallston, K. A., & Rothman, R. L. (2010). Self-Efficacy Links Health Literacy and Numeracy to Glycemic Control. *Journal of Health Communication, 15*, 146-158. doi: 10.1080/10810730.2010.499980

Osborn, C. Y., Cavanaugh, K., Wallston, K. A., White, R. O., & Rothman, R. L. (2009). Diabetes Numeracy: An overlooked factor in understanding racial disparities in glycemic control. *Diabetes Care, 32*(9), 1614-1619. doi: 10.2337/dc09-0425

Osborn, C. Y., Wallston, K. A., Shpigel, A., Cavanaugh, K., Kripalani, S., & Rothman, R. L. (2013). Development and validation of the General Health Numeracy Test

(GHNT). *Patient Education and Counseling, 91*(3), 350-356. doi: http://dx.doi.org/10.1016/j.pec.2013.01.001

Osborn, C. Y., Weiss, B.D., Davis, T.C., Skrepkauskas, S., Rodrigue, C., Bass, P.F., Wolf, M.S. (2011). Measuring Adult Literacy in Health Care: Performance of the Newest Vital Sign. *Am J Health Behav, 31*(Suppl 3), S36-S46.

Ownby, R. L., Acevedo, A., Waldrop-Valverde, D., Jacobs, R.J., Caballero, J., Davenport, R., Homs, A., Czaja, S.J., Lowenstein, D. (2013). Development and initial validation of a computer-administered health literacy assessment in Spanish and English: FLIGHT/VIDAS. *Patient Related Outcome Measures, 4*, 21-35.

Paasche-Orlow, M. K., & Wolf, M. S. (2007). The causal pathways linking health literacy to health outcomes. *Am J Health Behav, 31 Suppl 1*, S19-26. doi: 10.5555/ajhb.2007.31.supp.S19

Pajares, F. (2009). Information on Self-Efficacy. Retrieved 4.13.2013, from http://www.uky.edu/~eushe2/Pajares/self-efficacy.html#instruments

Parker, R. M., Baker, D. W., Williams, M. V., & Nurss, J. R. (1995). The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine, 10*(10), 537-541.

Pulgaron, E. R., Sanders, L. M., Patino-Fernandez, A. M., Wile, D., Sanchez, J., Rothman, R. L., & Delamater, A. M. (2014). Glycemic control in young children with diabetes: the role of parental health literacy. *Patient Educ Couns, 94*(1), 67-70. doi: 10.1016/j.pec.2013.09.002

Ratzan, S. C., Parker, R.M. (2000). National library of medicine current bibliographies in medicine: health literacy. In C. R. Selden, Zorn, M., Ratzan, S.C. (Ed.). Bethesda, MD: National Institutes of Health, US Department of Health and Human Services.

Richardson, F. C., Suinn, R.M. (1972). The Mathematics Anxiety Rating Scale. *Journal of Counseling Psychology, 19*, 551-554.

Ross, L. A., Frier, B. M., Kelnar, C. J. H., & Deary, I. J. (2001). Child and parental mental ability and glycaemic control in children with Type 1 diabetes. *Diabetic Medicine, 18*(5), 364-369. doi: 10.1046/j.1464-5491.2001.00468.x

Rothman, R. L., Housam, R., Weiss, H., Davis, D., Gregory, R., Gebretsadik, T., . . . Elasy, T. A. (2006). Patient Understanding of Food Labels: The Role of Literacy and Numeracy. *American Journal of Preventive Medicine, 31*(5), 391-398. doi: 10.1016/j.amepre.2006.07.025

Rothman, R. L., Montori, V. M., Cherrington, A., Pignone, M.P. (2008). Perspective: The Role of Numeracy in Health Care. *Journal of Health Communication, 13*(6), 583-595. doi: 10.1080/10810730802281791

Rothman, R. L., Yin, H. S., Mulvaney, S., Co, J. P., Homer, C., & Lannon, C. (2009). Health literacy and quality: focus on chronic illness care and patient safety. *Pediatrics, 124 Suppl 3*(Suppl), S315-326. doi: 10.1542/peds.2009-1163H

Rowlands, G., Khazaezadeh, N., Oteng-Ntim, E., Seed, P., Barr, S., & Weiss, B. D. (2013). Development and validation of a measure of health literacy in the UK: the newest vital sign. *BMC Public Health, 13*(1), 116. doi: 10.1186/1471-2458-13-116

Sanders, L. M., Federico, S., Klass, P., Abrams, M. A., & Dreyer, B. (2009). Literacy and child health: a systematic review. *Arch Pediatr Adolesc Med, 163*(2), 131-140. doi: 10.1001/archpediatrics.2008.539

Sanders, L. M., Shaw, J. S., Guez, G., Baur, C., & Rudd, R. (2009). Health literacy and child health promotion: implications for research, clinical care, and public policy. *Pediatrics, 124 Suppl 3*(S306-S314), S306-314. doi: 10.1542/peds.2009-1162G

Sarkar, U., Fisher, L., Schillinger, D. (2006). Is Self-Efficacy Associated with Diabetes Self-Management Across Race/Ethnicity and Health Literacy? *Diabetes Care, 29*(4), 823-829. doi: 10.2337/diacare.29.04.06.dc05-1615

Schapira, M., Fletcher, K., Ganschow, P., Walker, C., Tyler, B., Pozo, S., . . . Jacobs, E. (2011). The Meaning of Numbers in Health: Exploring Health Numeracy in a Mexican-American Population. *JGIM: Journal of General Internal Medicine, 26*(7), 705-711. doi: 10.1007/s11606-011-1645-5

Schapira, M. M., Fletcher, K. E., Gilligan, M. A., King, T. K., Laud, P. W., Matthews, B. A., . . . Hayes, E. (2008). A Framework for Health Numeracy: How Patients Use Quantitative Skills in Health Care. *Journal of Health Communication, 13*(5), 501-517. doi: 10.1080/10810730802202169

Schapira, M. M., Walker, C. M., Cappaert, K. J., Ganschow, P. S., Fletcher, K. E., McGinley, E. L., . . . Jacobs, E. A. (2012). The Numeracy Understanding in Medicine Instrument: A Measure of Health Numeracy Developed Using Item Response Theory. *Medical Decision Making, 32*(6), 851-865. doi: 10.1177/0272989x12447239

Schuett, V. (2010). *Low Protein Food List for PKU* (Third Edition ed.). Seattle: Author.

Schwartz, L. M., Woloshin, S., Black, W. C., & Welch, H. G. (1997). The role of numeracy in understanding the benefit of screening mammography. *Ann Intern Med, 127*(11), 966-972.

Schwartz, L. M., Woloshin, S., Welch, H.G. (2005). Can patients interpret health information? An assessment of the medical data interpretation test. *Medical Decision Making, 25*(3), 290-300. doi: 10.1177/0272989X05276860

Screening Technology and Research in Genetics Project. (2013). Genetics Fact Sheets for Parents: PKU. Retrieved 3/8/14, from http://www.newbornscreening.info/Parents/aminoaciddisorders/PKU.html#7

Silverstein, J., Klingensmith, G., Copeland, K., Plotnick, L., Kaufman, F., Laffel, L., . . . Clark, N. (2005). Care of Children and Adolescents With Type 1 Diabetes: A statement of the American Diabetes Association. *Diabetes Care, 28*(1), 186-212. doi: 10.2337/diacare.28.1.186

Singh, R. H., Rohr, F., Frazier, D., Cunningham, A., Mofidi, S., Ogata, B., . . . Van Calcar, S. C. (2014). Recommendations for the nutrition management of phenylalanine hydroxylase deficiency. *Genet Med, 16*(2), 121-131. doi: 10.1038/gim.2013.179

Smith, M. S., Wallston, K. A., & Smith, C. A. (1995). The development and validation of the Perceived Health Competence Scale. *Health Educ Res, 10*(1), 51-64.

Smith, T. W., Marsden, P., Hout, M., Kim, J. (2013) General Social Surveys, 1972-2012: Cumulative Codebook. *National Data Program for the Social Sciences Series*. Chicago: National Opinion Research Center.

Streisand, R., Swift, E., Wickmark, T., Chen, R., & Holmes, C. S. (2005). Pediatric Parenting Stress Among Parents of Children with Type 1 Diabetes: The Role of Self-Efficacy, Responsibility, and Fear. *Journal of Pediatric Psychology, 30*(6), 513-521. doi: 10.1093/jpepsy/jsi076

Streisand, R., Swift, E., Wickmark, T., Chen, R., Holmes, C.S. (2005). Pediatric Parenting Stress Among Parents with Children with Type 1 Diabetes: The Role of Self-Efficacy, Responsibility, and Fear. *Journal of Pediatric Psychology, 30*(6), 513-521.

Suinn, R. M., & Winston, E. H. (2003). The Mathematics Anxiety Rating Scale, a brief version: psychometric data. *Psychol Rep, 92*(1), 167-173.

Tao, B., Pietropaolo, M., Atkinson, M., Schatz, D., Taylor, D. (2010). Estimating the Cost of Type 1 Diabetes in the U.S.: A Propensity Score Matching Method. *PLoS ONE, 5*(7), e11501. doi: doi:10.1371/journal.pone.0011501

Tapia, M. M., G.E. (2004). An Instrument to Measure Mathematic Attitudes. *Academic Exchange Quarterly, 8*(2).

Taylor, J. F., Lata, R.S. (1993). *Why Can't I Eat That!: Helping Kids to Obey Medical Diets*. Saratoga, CA: R&E Publishers.

Trahms, C. M. (2008). PKU Self-Management Timeline. *Cristine M. Trahms Programs for Phenylketonuria - Seattle.* Retrieved 9/28/2013, from http://depts.washington.edu/pku/resources/timeline.html

U.S. Department of Health & Human Services. (2000). *Health People 2010: Understanding and Improving Health*. Washington, DC: U.S. Government Printing Office.

U.S. Department of Health & Human Services. (2011a). Healthy People 2020, Disparities. Retrieved January 28, 2013, from http://healthypeople.gov/2020/about/disparitiesAbout.aspx

U.S. Department of Health & Human Services. (2011b). Healthy People 2020, Maternal, Infant, and Child Health,. from http://www.healthypeople.gov/2020/topicsobjectives2020/objectiveslist.aspx?topicId=26

U.S. Department of Health & Human Services. (2013). Healthy People 2020: Health Communication and Health Information Technology. Retrieved 12/1/13, from http://healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=18

University of California San Francisco. (2013). Diabetes Education Online: Calculating Insulin Dose. Retrieved 11/22/13, from http://dtc.ucsf.edu/types-of-diabetes/type1/treatment-of-type-1-diabetes/medications-and-therapies/type-1-insulin-therapy/calculating-insulin-dose/

van der Bilj, J., van Poelgeest-Eeltink, A., Shortideg-Baggett, L. (1999). Psychometric properties of the diabetes management self-efficacy scale for patients with type 2 diabetes mellitus. *Journal of Advanced Nursing, 30*, 352-359.

Vernon, J. A., Trujillo, A., Rosenbaum, S., DeBuono, B. (2007). Low Health Literacy: Implications for National Health Policy. Retrieved 3/1/14, from http://sphhs.gwu.edu/departments/healthpolicy/CHPR/downloads/LowHealthLiteracyReport10_4_07.pdf

Virginia Department of Education. (2011). Workplace Readiness Skills Assessment. from https://www.ctecs.org/va-wrs-assessment.htm

Visschers, V. H. M., & Siegrist, M. (2010). When reduced fat increases preference. How fat reduction in nutrition tables and numeracy skills affect food choices. *Appetite, 55*, 730-733. doi: doi:10.1016/j.appet.2010.09.001

Vockley, J., Andersson, H. C., Antshel, K. M., Braverman, N. E., Burton, B. K., Frazier, D. M., . . . Berry, S. A. (2014). Phenylalanine hydroxylase deficiency: diagnosis and management guideline. *Genet Med, 16*(2), 188-200. doi: 10.1038/gim.2013.157

Waisbren, S. E., Noel, K., Fahrbach, K., Cella, C., Frame, D., Dorenbaum, A., & Levy, H. (2007). Phenylalanine blood levels and clinical outcomes in phenylketonuria: a systematic literature review and meta-analysis. *Mol Genet Metab, 92*(1-2), 63-70. doi: 10.1016/j.ymgme.2007.05.006

Waldrop-Valverde, D., Jones, D. L., Gould, F., Kumar, M., & Ownby, R. L. (2010). Neurocognition, Health-Related Reading Literacy, and Numeracy in Medication Management for HIV Infection. *AIDS Patient Care & STDs, 24*(8), 477-484. doi: 10.1089/apc.2009.0300

Waldrop-Valverde, D., Osborn, C., Rodriguez, A., Rothman, R., Kumar, M., & Jones, D. (2010). Numeracy Skills Explain Racial Differences in HIV Medication Management. *AIDS and Behavior, 14*(4), 799-806. doi: 10.1007/s10461-009-9604-4

Wallston, K. A., Rothman, R. L., & Cherrington, A. (2007). Psychometric properties of the Perceived Diabetes Self-Management Scale (PDSMS). *J Behav Med, 30*(5), 395-401. doi: 10.1007/s10865-007-9110-y

Walter, J. H., White, F. J., Hall, S. K., MacDonald, A., Rylance, G., Boneh, A., Francis, D. E., Shortland, G. J., Schmidt, M., Vail, A. (2002). How practical are recommendations for dietary control in phenylketonuria? *Lancet, 360*(9326), 55.

Wechsler, D. (2005). *Wechsler Individual Achievement Test 2nd Edition (WIAT II)*. London: The Psychological Corp.

Weiss, B. D., Mays, M.Z., Martz,W., et al.,. (2005). Quick assessment of literacy in primary care: the newest vital sign. *Annals of Family Medicine, 3*, 514-522.

Welsh, S. O., Davis, C., Shaw, A. (1993). *USDA's Food Guide: Background and Development*. Hyattsville, MD: Human Nutrition Information Service Retrieved from http://www.cnpp.usda.gov/Publications/MyPyramid/OriginalFoodGuidePyramids/FGP/FGPBackgroundAndDevelopment.pdf.

White, R. O., 3rd, Osborn, C. Y., Gebretsadik, T., Kripalani, S., & Rothman, R. L. (2011). Development and validation of a Spanish diabetes-specific numeracy measure: DNT-15 Latino. *Diabetes Technol Ther, 13*(9), 893-898. doi: 10.1089/dia.2011.0070

White, R. O., Wolff, K., Cavanaugh, K. L., & Rothman, R. (2010). Addressing Health Literacy and Numeracy to Improve Diabetes Education and Care. *Diabetes Spectrum, 23*(4), 238-243. doi: 10.2337/diaspect.23.4.238

WHO Commission on Social Determinants of Health. (2013). Social Determinants of Health: Key Concepts Retrieved 12/1/13, from http://www.who.int/social_determinants/thecommission/finalreport/key_concepts/en/

Wilkinson, G. S., Robertson,G.J. (2006). *Wide Range Achievement Test 4 Professional Manual*. Lutz, FL: Psychological Assessment Resources.

Williams, M. V., Parker, R. M., Baker, D. W., & et al. (1995). Inadequate functional health literacy among patients at two public hospitals. *JAMA, 274*(21), 1677-1682. doi: 10.1001/jama.1995.03530210031026

Williams, M. V., Parker, R., Baker, D. (1995). Inadequate functional health literacy among patients at two public hospitals. *Journal of the American Medical Association, 274*, 1677-1682.

Wilson, F. R., Pan, W., Schumsky, D.A. (2012). Recalculation of the Critical Values for Lawshe's Content Validity Ratio. *Measurement and Evaluation in Counseling and Development, 45*(3), 197-210.

Wolf, M. S., Wilson, E. A., Rapp, D. N., Waite, K. R., Bocchini, M. V., Davis, T. C., & Rudd, R. E. (2009). Literacy and learning in health care. *Pediatrics, 124 Suppl 3*(Suppl), S275-281. doi: 10.1542/peds.2009-1162C

Woodcock, R. W., McGrew, K.S., Mather, N. (2007). Woodcock-Johnson III. Retrieved 11/13/13

World Health Organization. (2009). 7th Global Conference on Health Promotion: Health literacy and health behaviour. from http://www.who.int/healthpromotion/conferences/7gchp/track2/en/

Wrona, R. M. (1979). A Clinical Epidemiologic Study of Hyperphenylalaninemia. *American Journal of Public Health, 69*(7), 673-679.

Wu, S. S., Barth, M., Amin, H., Malcarne, V., & Menon, V. (2012). Math anxiety in second and third graders and its relation to mathematics achievement. *Front Psychol, 3*(162), 162. doi: 10.3389/fpsyg.2012.00162

Yin, H. S., Johnson, M., Mendelsohn, A. L., Abrams, M. A., Sanders, L. M., & Dreyer, B. P. (2009). The Health Literacy of Parents in the United States: A Nationally Representative Study. *Pediatrics, 124*(Supplement 3), S289-S298. doi: 10.1542/peds.2009-1162E

Yin, H. S., Sanders, L. M., Rothman, R. L., Mendelsohn, A. L., Dreyer, B. P., White, R. O., . . . Perrin, E. M. (2012). Assessment of Health Literacy and Numeracy Among Spanish-Speaking Parents of Young Children: Validation of the Spanish Parental Health Literacy Activities Test (PHLAT Spanish). *Academic Pediatrics, 12*(1), 68-74. doi: http://dx.doi.org/10.1016/j.acap.2011.08.008

Zikmund-Fisher, B. J., Smith, D. M., Ubel, P. A., & Fagerlin, A. (2007). Validation of the Subjective Numeracy Scale: Effects of Low Numeracy on Comprehension of Risk Communications and Utility Elicitations. *Medical Decision Making, 27*(5), 663-671. doi: 10.1177/0272989x07303824

APPENDICES

Appendix A
Common Core State Standards Initiative 2012

Mathematics

Competency	CCSS	Description
Whole numbers		
Count whole numbers	K.CC.B.4	Understand the relationship between numbers and quantities; connect counting to cardinality.
Read whole numbers	K.CC.A.3	Write numbers from 0 to 20. Represent a number of objects with a written numeral 0-20 (with 0 representing a count of no objects).
Order and compare	K.CC.C.6	Identify whether the number of objects in one group is greater than, less than, or equal to the number of objects in another group, e.g., by using matching and counting strategies.
Write	K.CC.A.3	Write numbers from 0 to 20. Represent a number of objects with a written numeral 0-20 (with 0 representing a count of no objects).
	2.NBT.A.3	Read and write numbers to 1000 using base-ten numerals, number names, and expanded form
Add/Subtract	2.NBT.B.5	Fluently add and subtract within 100 using strategies based on place value, properties of operations, and/or the relationship between addition and subtraction.
	2.NBT.B.6	Add up to four two-digit numbers using strategies based on place value and properties of operations
Multiply/Divide	3.OA.A.4	Use multiplication and division within 100 to solve word problems in situations involving equal groups, arrays, and measurement quantities.
	5.NBT.B.5	Fluently multiply multi-digit whole numbers using the standard algorithm.
Fractions		
Understand / Read	3.NF.A.1	Understand a fraction 1/*b* as the quantity formed by 1 part when *a* whole is partitioned into *b* equal parts; understand a fraction *a*/*b* as the quantity formed by a parts of size 1/*b*.
Determine	3.G.A.2	Partition shapes into parts with equal areas. Express the area of each part as a unit fraction of the whole. *For example, partition a shape into 4 parts with equal area, and describe the area of each part as 1/4 of the area of the shape*.

Order or Compare	3.NF.A.3d	Compare two fractions with the same numerator or the same denominator by reasoning about their size. (Fractions with denominators 2, 3, 4, 6, 8.)
Write	3.NF.A.3b	Recognize and generate simple equivalent fractions, e.g., 1/2 = 2/4, 4/6 = 2/3.
Add/Subtract	4.NF.B.3a	Understand addition and subtraction of fractions as joining and separating parts referring to the same whole.
	4.NF.B.3d	Solve word problems involving addition and subtraction of fractions referring to the same whole and having like denominators.
Multiply/Divide	4.NF.B.4b	Understand a multiple of a/b as a multiple of 1/b, and use this understanding to multiply a fraction by a whole number.
	4.NF.B.4c	Solve word problems involving multiplication of a fraction by a whole number.
	5.NF.B.7c	Solve real world problems involving division of unit fractions by non-zero whole numbers and division of whole numbers by unit fractions
Decimals		
Write	4.NF.C.6	Use decimal notation for fractions with denominators 10 or 100
Compare	4.NF.C.7	Compare two decimals to hundredths by reasoning about their size.
Add/Subtract	5.NBT.B.7	Add, subtract, multiply, and divide decimals to hundredths
Multiply/Divide	5.NBT.B.7	Add, subtract, multiply, and divide decimals to hundredths
	6.NS.B.3	Fluently add, subtract, multiply, and divide multi-digit decimals using the standard algorithm for each operation.
Round	5.NBT.A.4	Use place value understanding to round decimals to any place
Measure		
Measure and Estimate Capacity and Weight Read simple scale	3MD.A.2	Measure and estimate liquid volumes and masses of objects using standard units of grams (g), kilograms (kg), and liters (l).[1] Add, subtract, multiply, or divide to solve one-step word problems involving masses or volumes that are given in the same units, e.g., by using drawings (such as a beaker with a measurement scale) to represent the problem.

Estimate linear measurements	2.MD.A.3	Estimate lengths using units of inches, feet, centimeters, and meters.
Ratio/Percent/ Proportion		
Use ratios	6.RP.A.1	Understand the concept of a ratio and use ratio language to describe a ratio relationship between two quantities.
Use percentages	6.RP.A.3c	Find a percent of a quantity as a rate per 100
Numerical Operations		
Convert units of measurement	6.RP.A.3d	Use ratio reasoning to convert measurement units; manipulate and transform units appropriately when multiplying or dividing quantities
Algebra		
Use expressions and formula equations	6.EE.A.2c	Evaluate expressions at specific values of their variables. Include expressions that arise from formulas used in real-world problems
Utilize tables	1.MD.C.4	Organize, represent, and interpret data with up to three categories.
Use calculator		
Time		
Understand / Record	2.MD.C.7	Tell and write time from analog and digital clocks to the nearest five minutes, using a.m. and p.m.
Sort and classify objects	K.MD.B.3	Classify objects into given categories; count the numbers of objects in each category and sort the categories by count.

Appendix B. Numeracy Content Skills for Medical Management Tasks in PKU

Context PKU	Task	Number Skills	CCSS Math Content[1]	Measures, Shape, & Space	CCSS Math Content[1]	Handling Data	CCSS Math Content[1]
Infant Formula	Understand recipe	Read whole numbers Read fractions	K.CC.A.3 3.NF.A.1	Measure weight and capacity	3.MD.A.2		
Infant Formula	Measure ingredients	Count whole numbers Order and compare whole numbers Order and compare fractions	K.CC.B.4 K.CC.C.6. 3NF.A.2	Measure weight and capacity Read simple scale	3.MD.A.2		
Infant Formula	Prepare portion to be served	Read whole numbers or fractions	K.CC.A.3 3.NF.A.1	Measure capacity Read simple scale	3.MD.A.2		
Infant Formula	Assess and record intake	Count whole numbers Count fractions Add and subtract whole numbers Subtract fractions Write whole numbers Write fractions Add fractions Use calculator	K.CC.B.4 3.NF.A.1 2.NBT.B.5 4.NF.B.3a K.CC.A.3 3.NF.A.3b 4.NF.B.3a	Measure and estimate capacity Understand time	3.MD.A.2 2.MD.C.7	Record time Record numerical information	2.MD.C.7 1.MD.C.4

Appendix B, continued. Numeracy Content Skills for Medical Management Tasks in PKU

Baby Food	Choose and serve food to meet PHE goal	Divide whole numbers Subtract whole numbers or fractions Compare whole numbers Multiply fractions Count whole numbers Count fractions Write whole numbers and fractions Add whole numbers and fractions	3.OA.A.4 2.NBT.B.5 4.NF.B.3a K.CC.C.6. 4.NF.B.4b K.CC.B.4 3.NF.A.1 K.CC.A.3 3.NF.A.3b 2.NBT.B.5 4.NF.B.3a	Convert units of measure Measure and estimate capacity Estimate linear measurements	5.MD.A.1 3.MD.A.2 2.MD.A.3	Use tables Record numerical information	1.MD.C.4
Food and Beverages	Choose and serve food to meet PHE goal. Retrieve data from book or food label. Determine PHE content of a food portion. Determine remaining PHE allowance per meal and choose food to meet it.	Count whole numbers Add and subtract whole numbers Add and subtract fractions or decimals Use ratio and proportion Multiply and divide whole numbers, fractions, or decimals Write whole numbers, fractions, decimals Round decimals	K.CC.B.4 2.NBT.B.5 4.NF.B.3a 5.NBT.B.7 6.RP.A.1 3.OA.A.4 4.NF.B.4b 5.NBT.B.7 K.CC.A.3 3.NF.A.3b 5.NBT.A.4	Convert units of measure Measure and estimate capacity Estimate linear measurements	5.MD.A.1 3.MD.A.2 2.MD.A.3	Use tables Record numerical information	1.MD.C.4
Food and Beverages-Acquisition	Shop for appropriate foods	Read, compare, multiply, and divide whole numbers Ratio and proportion	K.CC.A.3 K.CC.C.6 3.OA.A.4 6.RP.A.1	Convert units of measure	5.MD.A.1	Use tables Sort and classify objects	1.MD.C.4 K.MD.B.3

Appendix B, continued. Numeracy Content Skills for Medical Management Tasks in PKU

Food and Beverages-Food variety	Prepare a new food from a recipe, determine serving size	Read whole numbers Read fractions Count whole numbers Order and compare whole numbers Order and compare fractions Divide whole numbers .	K.CC.A.3 3.NF.A.1 K.CC.B.4 K.CC.C.6. 3NF.A.2 3.OA.A.4	Measure weight and capacity Read simple scale Understand time Convert units of measure	3.MD.A.2 2.MD.C.7 5.MD.A.1	Use tables Collect and record numerical information	1.MD.C.4
Protein Products	Prepare and serve protein products	Count and add whole numbers	K.CC.B.4 2.NBT.B.5	Measure capacity	3.MD.A.2		
Laboratory Results	Understand lab results report	Compare whole numbers or decimals	K.CC.C.6.				

[1] Common Core Math Standards (Common Core State Standards Initiative, 2012)

Appendix C. Numeracy Content Skills for Medical Management Tasks in T1D

Context T1D	Task	Number Skills	CCSS Math Content[1]	Measures, Shape, & Space	CCSS Math Content[1]	Handling Data	CCSS Math Content[1]
Food and Beverages	Schedule meals and snacks Choose and serve food to meet CHO goal. Retrieve data from book or food label. Calculate CHO content of a food portion.[5] Determine remaining CHO allowance per meal and choose food to meet it.	Count whole numbers Add and subtract whole numbers Read fractions Determine fractions[7] Add and subtract fractions or decimals Multiply and divide whole numbers, fractions, or decimals[1] Round decimals[1] Compare whole numbers or fractions Ratio and proportion[1]	K.CC.B.4 2.NBT.B.5 3.NF.A.1 4.NF.B.3a 5.NBT.B.7 3.OA.A.4 4.NF.B.4b 5.NBT.B.7 5.NBT.A.4 K.CC.C.6. 3NF.A.2 6.RP.A.1	Understanding of time Convert units of measure[1] Measure and estimate capacity Estimate measurements	2.MD.C.7 5.MD.A.1 3.MD.A.2 2 MD.A.3	Use tables Record numerical information	1.MD.C.4
Food and Beverages: acquisition	Shop for appropriate foods	Read, multiply, and divide whole numbers Ratio and proportion	K.CC.A.3 3.OA.A.4 6.RP.A.1	Convert units of measurement	5.MD.A.1	Use tables	1.MD.C.4

Appendix C, continued. Numeracy Content Skills for Medical Management Tasks

Food and Beverages: food variety	Prepare a new food from a recipe, determine serving size	Read whole numbers Read fractions Count whole numbers Order and compare whole numbers Order and compare fractions Divide whole numbers	K.CC.A.3 3.NF.A.1 K.CC.B.4 K.CC.C.6. 3NF.A.2 3.OA.A.4	Measure weight and capacity Read simple scale Understand time Convert units of measurement	3.MD.A.2 2.MD.C.7 5.MD.A.1		
Blood glucose monitoring	Identify target glucose level[7] Read blood glucose meter Interpret glucose meter reading – determine whether in range[6]	Read whole numbers Order and compare whole numbers	K.CC.A.3 K.CC.C.6.	Read simple scale	3.MD.A.2	Use graphs, charts Collect and record numerical information	1.MD.C.4

Appendix C, continued. Numeracy Content Skills for Medical Management Tasks

Medication Dosing	Calculate insulin dose, based on CHO intake and/or blood glucose level[6] Schedule medication Interpret insulin correction scale table [5]	Add, subtract, multiply and divide whole numbers Use expressions and formulas Use percentages Use ratios	2.NBT.B.5 3.OA.A.4 6.EE.A.2c 6.RP.A.3c 6.RP.A.1	Understanding of time	2.MD.C.7	Use tables	1.MD.C.4
Medication Administra -tion	Identify correct amount of insulin on syringe[5]	Compare decimals	4.NF.C.7	Read simple scales	3.MD.A.2		
Exercise	Calculate CHO intake needed for exercise duration[5] Measure duration of exercise	Use expressions and formulas (equations)	6.EE.A.2c	Understanding of time	2.MD.C.7		

[1]Common Core State Standards (Common Core State Standards Initiative, 2012)
[2] Ginsburg (Ginsburg, 2006)
[3]Mulvaney(Mulvaney et al., 2013)
[4]Huizinga 2008 (M.M. Huizinga et al., 2008)
[5]Cavanaugh (Cavanaugh et al., 2008) :
[6] University of California (University of California San Francisco, 2013)
[7]Kerr(Kerr, 2010)

Appendix D
Cognitive Numeracy Tools for Adults

Name	Description	Application	Reference
Comprehensive Adult Student Assessment System (CASAS)	Applied mathematics problems	Adult education or workplace assessment.	(CASAS, 2013)
Test of Adult Basic Education (TABE)	Computation and applied mathematics sections	Pre- and post-testing, placement	(CTB Research, 2013)
Woodcock-Johnson –III Tests of Achievement, Math section	Applied Problem Set	Intellectual and cognitive testing	(Woodcock, 2007)
Wechsler Individual Achievement Test (WIAT-III), Mathematics Subtests	Math Reasoning, Numerical Operations, Math Fluency	Assess academic achievement	(Wechsler, 2005)
Wide Range Achievement Test (WRAT-4) Math Computation Subset	Counting, identifying numbers, simple oral problems, written mathematics problems	Psychological, educational, vocational assessments	(Wilkinson, 2006)
National Assessment of Adult Literacy Survey – Quantitative section	National survey instrument	Evaluation of national literacy trends	(Kutner, 2007)
Adult Skills for Life Survey, Maths section	Numeracy skills test in UK	National survey, adult education	(Excellence Gateway, 2013)
Rapid Estimate of Adult Literacy in Medicine (REALM)	Word recognition and pronunciation	General health literacy	(Davis et al., 1993)
Test of Functional Health Literacy in Adults (TOFHLA), Numeracy Portion, Shortened TOFHLA	Health literacy test with a math component	Research, clinical assessment	(D. W. Baker et al., 1999)
Newest Vital Sign (NVS), NVS-UK	Documents and quantitative skills. Interpretation of nutrition label	Clinical assessment	(Weiss, 2005) UK adaptation: (Rowlands et al., 2013)
Objective Numeracy Scale	Probability and Percentages	Research tool	(Lipkus et al., 2001)
Subjective Numeracy Test (SNS)	Self-rating of ability and affect	Research tool	(Fagerlin et al., 2007)
Numeracy Understanding in Medicine (NUMi)	Health numeracy tool, including statistics	Research and clinical tool	(Marilyn M. Schapira et al., 2012)

Medical Data Interpretation Test	Interpretation of medical statistics	Research, inform teaching strategies	(L. M. Schwartz, Woloshin, S., Welch, H.G., 2005)
Fostering Literacy for Good Health Today (FLIGHT), Viva Desarollando Amplia Salude (VIDAS)	Health literacy, numeracy, use of healthcare system. Computer administered. English and Spanish versions	Clinical assessment	(Ownby, 2013)
Health Literacy Skills Instrument (HLSI) and Short Form (HLSI–SF)	Health literacy and numeracy assessment	Surveillance, research, evaluation of interventions	(Bann et al., 2012)
General Health Numeracy Test (GHNT)	Health numeracy	General health	(C. Y. Osborn et al., 2013)
Parental Health Literacy Assessment Test (PHLAT) PHLAT-10 PHLAT Spanish	Health literacy skills: reading food labels, dosing OTC medicine etc.	Caregivers of children <13 months of age	(Kumar et al., 2010) (Yin et al., 2012)
Diabetes Numeracy Test (DNT) DNT-15 DNT-Spanish	Measure of numeracy skills used in diabetes	Research and clinical evaluation	(M. M. Huizinga, T. A. Elasy, et al., 2008)

Appendix E
Selected Affective Numeracy Assessment Tools

Name	Description	Application	Reference
Math Anxiety Rating Scale (MARS) 98 question version	Expected anxiety in math-related situations, mostly classroom, some daily life situations	College freshmen to seniors	(Richardson, 1972)
Math Attitude Inventory	Attitude - value and enjoyment of math	College freshmen	(Aiken, 1974)
Fennema-Sherman Mathematics Attitude Scale	Attitude, self-efficacy, motivation, and anxiety	High school	(Fennema, 1976)
Math Anxiety Rating Scale (MARS) 30 question version	Expected anxiety in math-related situations, mostly classroom, some daily life situations	College freshmen to seniors	(Suinn & Winston, 2003)
Attitude Towards Mathematics Inventory	Self-efficacy, value, anxiety, motivation	High school	(Tapia, 2004)
Mathematics Attitude Scale-Revised	Positive and negative emotions about math	College	Bai, 2008 #117}
Scale for Early Mathematic Anxiety (SEMA)	Expected anxiety	7-9 year old second and third graders	(Wu et al., 2012)

Appendix F

Recruitment Tool

Opportunity to Participate in Research about PKU!

We are looking for parents/guardians to participate in study about PKU

To be eligible:

- Your child is older than 12 months but less than 12 years
- This is your oldest child with PKU.
- The child has not been on Kuvan in the past 6 months
- Child has classic PKU, not hyperphenylalanemia (mild PKU)

Benefits to you: Help us learn about how clinics can help all families to take care of their children with PKU.

How long does it take? About 30-45 minutes
In appreciation of your time, you will receive a gift card for $15 for your choice of Target or Wal-Mart stores.

Where does it happen? You decide:

- Your clinic
- At a PKU Walk or other community event
- A place nearby that is convenient to you

What does it involve?

- Fill out some surveys and answer questions
- Allow us to contact your child's clinic and obtain the latest labs.

Interested?

Please look for our table at this event, or contact us to set up an appointment:

Email: dcpant01@louisville.edu

Call (502) 588-0910

This research is being conducted by:
Richard W. Wilson, DHSc, MPH
School of Public Health and Information Sciences
University of Louisville
485 E. Gray Street
Louisville, KY 40202
(502) 852-3443 Richard.wilson@lousiville.edu

IRB Approval

Expiration Date:

Appendix G
Parental Self-Efficacy Scale for Diabetes Management

Parent Survey: Taking Care of a Child with Type 1 Diabetes

INSTRUCTIONS: This is a survey that was created to measure how well you feel you take care of **your child's diabetes.** Each statement is a statement of belief that you may or may not agree with. Next to each statement is a scale with a range from strongly disagree (1) to strongly agree (2). Please respond to each statement by circling one number next to it. Choose your response carefully, and make sure it is true for YOU.

	Strongly Disagree				Strongly Agree
1. It is hard for me to find ways to solve problems that occur in dealing with my child's diabetes.	1	2	3	4	5
2. When I try to change things I don't like about my child's diabetes it doesn't work.	1	2	3	4	5
3. I take care of my child well when it comes to his/her diabetes.	1	2	3	4	5
4. I am able to deal with things related to my child's diabetes as well as others .	1	2	3	4	5
5. I am successful when it comes to projects I do to take care of my child's diabetes.	1	2	3	4	5
6. Usually, my plans to take care of my child's diabetes don't work out.	1	2	3	4	5
7. No mater how hard I try, taking care of my child's diabetes doesn't turn out the way I like.	1	2	3	4	5
8. I'm usually able to accomplish the goals I set in trying to take care of my child's diabetes.	1	2	3	4	5

Appendix H
Parental Self-Efficacy Scale for PKU Management

Parent Survey: Taking Care of a Child with PKU

INSTRUCTIONS: This is a survey that was created to measure how well you feel you take care of **your child's PKU.** Each statement is a statement of belief that you may or may not agree with. Next to each statement is a scale with a range from strongly disagree (1) to strongly agree (2). Please respond to each statement by circling one number next to it. Choose your response carefully, and make sure it is true for YOU.

	Strongly Disagree				Strongly Agree
1. It is hard for me to find ways to solve problems that occur in dealing with my child's PKU.	1	2	3	4	5
2. When I try to change things I don't like about my child's PKU it doesn't work.	1	2	3	4	5
3. I take care of my child well when it comes to his/her PKU.	1	2	3	4	5
4. I am able to deal with things related to my child's PKU as well as others .	1	2	3	4	5
5. I am successful when it comes to projects I do to take care of my child's PKU.	1	2	3	4	5
6. Usually, my plans to take care of my child's PKU don't work out.	1	2	3	4	5
7. No mater how hard I try, taking care of my child's PKU doesn't turn out the way I like.	1	2	3	4	5
8. I'm usually able to accomplish the goals I set in trying to take care of my child's PKU.	1	2	3	4	5

Appendix I

Daily-Life Mathematics Attitude Scale Survey: Feelings about Numbers

Thank you for agreeing to participate in this survey. THESE QUESTIONS ARE BEING USED FOR RESEARCH PURPOSES ONLY. NO ONE WILL KNOW WHICH RESPONSES YOU PICKED.

Directions

Please read the statements below and circle the response that best describes your feelings. There are no right or wrong answers. Circle the response that is true for you.

1. I don't usually worry about being able to use numbers to solve problems.

Strongly Agree *Somewhat Agree* *Neutral* *Somewhat Disagree* *Strongly Disagree*

2. When a situation involving numbers arises that I can't immediately figure out, I stick with it until I have the answer.

Strongly Agree *Somewhat Agree* *Neutral* *Somewhat Disagree* *Strongly Disagree*

3. Math makes me feel uneasy and confused.

Strongly Agree *Somewhat Agree* *Neutral* *Somewhat Disagree* *Strongly Disagree*

4. I do as little work with numbers as possible.

Strongly Agree *Somewhat Agree* *Neutral* *Somewhat Disagree* *Strongly Disagree*

5. Math is enjoyable and stimulating to me.

Strongly Agree *Somewhat Agree* *Neutral* *Somewhat Disagree* *Strongly Disagree*

6. Math makes me feel uncomfortable, restless, irritable, and impatient.

Strongly Agree *Somewhat Agree* *Neutral* *Somewhat Disagree* *Strongly Disagree*

7. I like math puzzles.

Strongly Agree | *Somewhat Agree* | *Neutral* | *Somewhat Disagree* | *Strongly Disagree*

8. The challenge of figuring out a problem using numbers does not appeal to me.

Strongly Agree | *Somewhat Agree* | *Neutral* | *Somewhat Disagree* | *Strongly Disagree*

9. I don't understand how some people can spend so much time on math and seem to enjoy it.

Strongly Agree | *Somewhat Agree* | *Neutral* | *Somewhat Disagree* | *Strongly Disagree*

10. I get a sinking feeling when I think of trying to figure out a situation using numbers.

Strongly Agree | *Somewhat Agree* | *Neutral* | *Somewhat Disagree* | *Strongly Disagree*

11. I do as little work with numbers as possible.

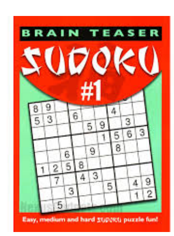
Strongly Agree | *Somewhat Agree* | *Neutral* | *Somewhat Disagree* | *Strongly Disagree*

12. Math usually makes me feel uncomfortable and nervous.

Strongly Agree | *Somewhat Agree* | *Neutral* | *Somewhat Disagree* | *Strongly Disagree*

13. Math puzzles are boring.

Strongly Agree | *Somewhat Agree* | *Neutral* | *Somewhat Disagree* | *Strongly Disagree*



14. Math doesn't scare me at all.

Strongly Agree	*Somewhat Agree*	*Neutral*	*Somewhat Disagree*	*Strongly Disagree*

15. Once I start trying to work on a math puzzle, I find it hard to stop.

Strongly Agree	*Somewhat Agree*	*Neutral*	*Somewhat Disagree*	*Strongly Disagree*

16. Figuring out a situation that involves numbers does not appeal to me.

Strongly Agree	*Somewhat Agree*	*Neutral*	*Somewhat Disagree*	*Strongly Disagree*

Appendix J
Demographic Data Form - PKU

Information About You and Your Child

Thank you for participating in this research project. We would like some information about yourself and your child. Please answer the questions below. This information will not be shared with anyone, and your name will not be on the questionnaire, so it cannot be connected with you. Thank you.

How old was your child on her/his last birthday?
______________ years
How old were you on your last birthday?
______________ years
What race do you consider yourself?
____
For how many years have you managed your child's special diet ?
______________years

Please place a check mark in front of the highest grade or education level you've completed:

____No formal education	____1 year of vocational / business / technical school
____Kindergarten	____2 years of vocational / business/ technical school
____1st Grade	____1 year of undergraduate education
____2nd Grade	____2 years of undergraduate education
____3rd Grade	(Associate's Degree)
____4th Grade	____3 years of undergraduate education
____5th Grade	____4 years of undergraduate education
____6th Grade	(Bachelor's degree)
____7th Grade	____1 year of post-graduate education
____8th Grade	____2 years of post-graduate education
____9th Grade	(Master's degree)
____10th Grade	____3 years of post-graduate education
____11th Grade	____4 or more years of post-graduate education
____12th Grade (or GED)	(PhD, MD, JD, DDS, DVM etc.)

Looking at the list of educational levels above, at which level of education did you take your last math class? Please write it here____________________.

Would you describe the place where you live as......

________Big city
________Suburb, Outskirts
________Medium-sized city or town
________Small town
________Farm, or live in the country

How do you manage your child's diet? Put a check by the statement that is closest to what you do:

___Count milligrams of phe (phenylalanine)
___Count grams of protein
___Count exchanges (1 exchange = 15 mg of phe)
___ Don't count - I know what foods my child can and cannot have
___ Other:
Please explain:____

What type of insurance does your child have?

______ Public insurance such as Medicaid, Passport, Coventry Cares, Humana CareSource, Wellcare, usually through the state government.

_______ Private insurance such as Anthem Blue Cross/BlueShield, United Healthcare, Tricare, Humana, Aetna, or other policy, usually through an employer

How many people are in your household? ________ How many adults? ________

What was your total family income, from all sources, from last year - 2013?

This includes salaries, public aid (welfare), Social Security or other pension, child support. It is the total income you listed on your taxes, before deductions.

Look at the income category list, and write here the letter of your income category _____

A	UNDER $1, 000	N	$60,000 TO 64,999
B	$1 000 TO 4,999	O	$65,000 TO 69,999
C	$5 000 TO 9,999	P	$70,000 TO 74,000
D	$10,000 TO 14,999	Q	$75,000 TO 79,999
E	$15,000 TO 19,999	R	$80,000 TO 84,999
F	$20,000 TO 24,999	S	$85,000 TO 89,999
G	$25,000 TO 29,999	T	$90,000 TO 94,999
H	$30,000 TO 34,999	U	$95,000 TO 99,999
I	$35,000 TO 39,999	V	$100,000 TO 124,999
J	$40,000 TO 44,999	W	$125,000 TO 149,999
K	$45,000 TO 49,999	X	$150,000 TO 199,999
L	$50,000 TO 54,999	Y	$200,000 or over
M	$55,000 TO 59,999		

THANK YOU FOR YOUR TIME TODAY!

Appendix K
Demographic Data Form - T1D

Information About You and Your Child

Thank you for participating in this research project. We would like some information about yourself and your child. Please answer the questions below. This information will not be shared with anyone, and your name will not be on the questionnaire, so it cannot be connected with you. Thank you.

How old was your child on her/his last birthday?
______________ years

How old were you on your last birthday?
______________ years

What race do you consider yourself?
____

For how many years have you managed your child's special diet ?
______________years

Please place a check mark in front of the highest grade or education level you've completed:

____No formal education
____Kindergarten
____1st Grade
____2nd Grade
____3rd Grade
____4th Grade
____5th Grade
____6th Grade
____7th Grade
____8th Grade
____9th Grade
____10th Grade
____11th Grade
____12th Grade (or GED)

____1 year of vocational / business / technical school
____2 years of vocational / business/ technical school
____1 year of undergraduate education
____2 years of undergraduate education (Associate's Degree)
____3 years of undergraduate education
____4 years of undergraduate education (Bachelor's degree)
____1 year of post-graduate education
____2 years of post-graduate education (Master's degree)
____3 years of post-graduate education
____4 or more years of post-graduate education (PhD, MD, JD, DDS, DVM etc.)

Looking at the list of educational levels above, at which level of education did you take your last math class? Please write it here____________________.

Would you describe the place where you live as......

________Big city
________Suburb, Outskirts
________Medium-sized city or town
________Small town
________Farm, or live in the country

How do you manage your child's diet? Put a check by the statement that is closest to what you do:

___Count grams of carbs
___Sometimes count and sometimes estimate grams of carbs
___Estimate grams of carbs
___ Sometimes estimate, sometimes don't keep track of grams of carbs
___Don't keep track of carbs at all
___ Other: Please explain:____

What type of insurance does your child have?
______ Public insurance such as Medicaid, Passport, Coventry Cares, Humana CareSource, Wellcare, usually through the state government.

_______ Private insurance such as Anthem Blue Cross/BlueShield, United Healthcare, Tricare, Humana, Aetna, or other policy, usually through an employer

How many people are in your household? ________ How many adults? ________

What was your total family income, from all sources, from last year - 2013?
This includes salaries, public aid (welfare), Social Security or other pension, child support. It is the total income you listed on your taxes, before deductions.

Look at the income category list, and write here the letter of your income category _____

A	UNDER $1, 000		
B	$1 000 TO 4,999	N	$60,000 TO 64,999
C	$5 000 TO 9,999	O	$65,000 TO 69,999
D	$10,000 TO 14,999	P	$70,000 TO 74,000
E	$15,000 TO 19,999	Q	$75,000 TO 79,999
F	$20,000 TO 24,999	R	$80,000 TO 84,999
G	$25,000 TO 29,999	S	$85,000 TO 89,999
H	$30,000 TO 34,999	T	$90,000 TO 94,999
I	$35,000 TO 39,999	U	$95,000 TO 99,999
J	$40,000 TO 44,999	V	$100,000 TO 124,999
K	$45,000 TO 49,999	W	$125,000 TO 149,999
L	$50,000 TO 54,999	X	$150,000 TO 199,999
M	$55,000 TO 59,999	Y	$200,000 or over

THANK YOU FOR YOUR TIME TODAY!

Appendix L
Association Between Peripheral Variables

Blood Levels by Community Type

Community Type	Mean	N	Std. Deviation
Big City	6.7761	10	.89691
Suburb, Outskirts	7.2808	27	1.23359
Medium-sized City or Town	7.8102	22	1.14161
Small Town	8.2508	18	1.40958
Farm or In the Country	8.1469	20	1.35196
Total	7.7074	97	1.31371

ANOVA Table

		Sum of Squares	df	Mean Square	F	Sig.
Blood Levels * Community Type	Between Groups	22.999	4	5.750	3.707	.008
	Within Groups	142.680	92	1.551		
	Total	165.679	96			

Appendix L, Continued
Association Between Peripheral Variables

Above Goal by Community Type

Community Type	Mean	N	Std. Deviation
Big City	.2773	10	.33115
Suburb, Outskirts	.5640	27	.86308
Medium-sized City or Town	.9167	22	.93933
Small Town	1.4020	18	1.11629
Farm or In the Country	1.3434	20	1.29138
Total	.9306	97	1.05604

ANOVA Table

		Sum of Squares	df	Mean Square	F	Sig.
Above Goal * Community Type	Between Groups	15.309	4	3.827	3.838	.006
	Within Groups	91.753	92	.997		
	Total	107.062	96			

Appendix L, Continued
Association Between Peripheral Variables

Blood Levels by Insurance Type

Insurance Type	Mean	N	Std. Deviation
Public	7.7992	39	1.41848
Private	7.6351	55	1.24035
None	7.8401	3	1.65432
Total	7.7074	97	1.31371

ANOVA Table

		Sum of Squares	df	Mean Square	F	Sig.
Blood Levels * Insurance Type	Between Groups	.669	2	.335	.191	.827
	Within Groups	165.010	94	1.755		
	Total	165.679	96			

Above Goal by Insurance Type

Insurance Type	Mean	N	Std. Deviation
Public	1.2857	39	1.23716
Private	.6667	55	.84942
None	1.1535	3	.72082
Total	.9306	97	1.05604

ANOVA Table

		Sum of Squares	df	Mean Square	F	Sig.
Above Goal * Insurance Type	Between Groups	8.899	2	4.450	4.261	.017
	Within Groups	98.162	94	1.044		
	Total	107.062	96			

CURRICULUM VITAE

NAME: Diana Cardina Pantalos

ADDRESS: Department of Pediatrics
Weisskopf Child Evaluation Center
University of Louisville
571 S. Floyd Street, Suite 100
Louisville, KY 40202

EDUCATION &TRAINING:

B.S., Home Economics
Major - Food and Nutrition
Ohio State University
1972-1975

M.S., Human Nutrition
Ohio State University
1975-1977

Ph.D., Public Health Science
Concentration in Health Promotion
University of Louisville
2011-2015

PROFESSIONAL SOCIETIES:

American Academy of Nutrition and Dietetics:
Registered Dietitian/Nutritionist

Genetic and Metabolic Dietitians International

Kentucky Academy of Nutrition and Dietetics

PROFESSIONAL WORK EXPERIENCE:

University of Louisville, Department of Pediatrics
Weisskopf Center for Evaluation of Children, Louisville, KY
Metabolic Nutritionist Sr, 2006 - present
Feeding Program Nutritionist, 2003 - present

Kentucky First Steps (Early Intervention Program)
Nutritionist, 2001 - 2006

Kosair and Norton Hospitals, Louisville, KY
Clinical Dietitian, 2001

Primary Children's Medical Center, Salt Lake City, UT
Clinical Dietitian, 1984-1990, 1996-2000,
Administrative Dietitian, 1994 -1996

Critical Care America, Salt Lake City, UT
Clinical Dietitian, 1988 - 1994

Children's Hospital Medical Center, Columbus, Ohio
Nutrition Support Team Dietitian, 1981 - 1984
Clinical Dietitian, 1980 - 1981

Columbus Health Department, Columbus, Ohio
WIC Nutritionist, 1977 - 1980

NATIONAL MEETING PRESENTATIONS

Dietary Treatment Non-Adherence in Metabolic Disorders: When Is It Child Neglect? 14th Abbott Nutrition Metabolic Conference. Nashville, TN, June 2013

Pantalos, D., Kinkus, K., Asamoah, A., Goodin, K. Pre-existing Malnutrition Alters Protein Management in Adult Presentation of Metabolic Disorders. Poster presentation. *Genetic and Metabolic Dietitians International, Third International Metabolic Nutrition Conference,* Baltimore, April 2010.

Pantalos, D. A resource for the Use of MCT Oil in Food Facilitates Adjustments in Fatty Acid Intake Ratios for Treatment of Long-Chain Fatty Acid Oxidation Disorders. *Genetic and Metabolic Dietitians International, Second International Metabolic Nutrition Conference,* Atlanta, April 2008.

Long Chain Fatty Acid Disorders: Food Preparation with MCT Oil. Fatty Oxidation Disorders /Organic Acidemia Association National Metabolic Conference, Pittsburgh, PA, July 2008.

Assessment and Treatment of Feeding Disorders in Children with Autism Spectrum Disorders. American Occupational Therapy Association Annual Conference, St. Louis, MO, April 2007.

Assessment and Treatment of Feeding in Children with Autism. Autism Society of America 36th National Conference, Nashville, TN, July 2005.

Pantalos, D., Metos, J. A Ten-Step Process for Achieving Nutrition Support Team Strategic Goals: A Successful Move into Home Care. Poster presentation. *American Society for Parenteral and Enteral Nutrition 23rd Clinical Congress, 1999.*

Pantalos, D. A Food Safety Checklist for the Home Nutrition Support Dietitian Counseling Immune-Suppressed Patients. Poster presentation. *American Society for Parenteral and Enteral Nutrition 17th Clinical Congress*, 1993.

Pantalos, D. Nutritional Assessment in the Home: Practical Aspects for the Dietitian. Poster presentation. *American Society for Parenteral and Enteral Nutrition 15th Clinical Congress*, 1991.

Giles, V., Pantalos, D., Book, L. Severe Metabolic Acidosis with Temporary Neurological Dysfunction in a Child with Short Bowel Syndrome. Poster presentation. *American Society for Parenteral and Enteral Nutrition 15th Clinical Congress*, 1991.

Pantalos, D., Tucker, E., Crouse, S., Book, L. Unexpected Successful Transition Off Home TPN Despite a Very Short Bowel in a Young Infant. Poster presentation. *American Society for Parenteral and Enteral Nutrition 14th Clinical Congress*, 1990.

Tucker, E., Pantalos, D., Crouse, S., Wood, S. TPN Without Hospitalization: Initiation to Completion in the Home. Poster presentation. *American Society for Parenteral and Enteral Nutrition 14th Clinical Congress Program Manual,* p.444, 1990.

Pantalos, D., Crouse, S., Tucker, E. Multidisciplinary Approach to Monitoring of Home TPN Patients. Poster presentation. *American Society for Parenteral and Enteral Nutrition 14th Clinical Congress,* 1989.

PUBLICATIONS IN REFEREED JOURNALS

Pantalos, D.C. Home Health Care: A New Worksite for Dietitians Monitoring Nutrition Support. *J Am Diet Assoc* 93: 1146-51, 1993.

Ginn-Pease, M.E., Pantalos, D., King, D.R. TPN-Associated Hyperbilirubinemia: A Common Problem in Newborn Surgical Patients *J Ped Surg* 20: 436-439, 1985.

INVITED PRESENTATIONS

Metabolic Disorders and the Community Healthcare Professional: Newborn Screening Brings New Diagnoses to Light. Kentucky Public Health Association 60th Annual Convention, Louisville, KY, April 2008.