PREVALENCE AND PREDICTORS OF FOOD INSECURITY IN CHILDREN WITH HEMOPHILIA

By

Sarah Kathryn Ziha

A THESIS

Submitted to the Faculty of the Graduate Programs in Human Nutrition

and the Oregon Health & Science University

School of Medicine

in partial fulfillment of

the requirements for the degree of

Master of Science in Clinical Nutrition

June 2013

School of Medicine

Oregon Health & Science University

CERTIFICATE OF APPROVAL

This is to certify I have read the Master's thesis of

Sarah Kathryn Ziha

And approve the research outlined herein

Diane Stadler, PhD, RD, LD

Elizabeth Adams, PhD, RD, LD

Michael Recht, PhD, MD

TABLE OF CONTENTS

List of Abbreviations and Acronyms

BMI	Body Mass Index
CDC	Centers for Disease Control and Prevention
CHC	Childhood Hunger Coalition
CPS	Current Population Survey
HFSS	Household Food Security Survey
NHANES	National Health and Nutrition Examination Survey
NSBP	National School Breakfast Program
OHSU	Oregon Health & Science University
SFSP	School Food Service Program
SLP	School Lunch Program
SNAP	Supplemental Nutrition Assistance Program
TANF	Temporary Aid for Needy Families
US	United States
USDA	United States Department of Agriculture
WIC	Supplemental Nutrition Program for Women, Infants, and Children

List of Figures

List of Tables

Acknowledgements

First I would like to thank my mentor, Dr. Elizabeth Adams, for offering to bring me on to this research project. I have appreciated your guidance and support and I am grateful to have had the opportunity to study something as globally relevant as food insecurity. This thesis has forever changed my perspective of my own nutrition practice to necessarily include food security screening and intervention.

To my committee members, Dr. Diane Stadler and Dr. Michael Recht, thank you very much for all of your time and effort to provide guidance, support, and endless suggestions for revision. My work is certainly more thorough and polished because of your keen eyes and constant inspiration to push my thinking and subsequent writing beyond what I am capable of on my own. A special thanks goes to Michael Lasarev (Research Associate, CROET), for statistical consultation.

To The Hemophilia Center at Oregon Health & Science University, thank you for caring immensely for your patients and for recognizing the importance of food security screening and intervention. Your work is already encouraging other health care providers to follow your example and so many other children may one day suffer less from food insecurity because of your initiative.

And finally, to my husband, Ryan; my parents, Joe and Kathy; and my closest friends—your unwavering love, support, and encouragement have seen me through every moment and effort of this project. I could not have accomplished this incredible goal without you.

Abstract

Background: Food insecurity, the limited or uncertain availability of nutritionally adequate and safe food, negatively affects children's development and health. Households including children with hemophilia may be at increased risk for food insecurity due to hemophilia-related medical expenses.

Objectives: The purpose of this pilot study was to determine the prevalence and predictors of food insecurity among children with hemophilia and their families.

Methods: Data on household food insecurity and health status, as assessed at annual comprehensive clinical appointments of children with hemophilia between May 2012-January 2013, were obtained by chart review. Descriptive statistics were applied to summarize participant characteristics. Chi-Square analyses, t-testing, and logistic regression models were used to demonstrate associations between food security status and participant characteristics.

Results: Data were available for 42 male participants, aged 0-17 years. By severity, 42.9% had mild or moderate hemophilia, and 57.1% severe. Sample prevalence of household food insecurity was 16.7% (95% CI, 5.4-28.0%), lower than the national prevalence among all households with children. Food insecurity was rare among households with children with mild and moderate disease (5.6%; 95% CI, 0-16.2%) and concentrated among households with children with severe disease (25.0%; 95% CI, 7.7-42.3%). Households with children who were older, taller, heavier, had higher BMI, or were a minority race or ethnicity were at increased risk for food insecurity (all P>0.05).

Conclusions: Households with children with severe hemophilia are at increased risk for food insecurity. This study provides pilot data showing the need for screening and linkage to resources as a routine part of care, and demonstrates a need for improved understanding of the predictors of food insecurity in households with children with hemophilia.

Chapter I

Introduction

Problem and Significance

Hemophilia is the congenital deficiency of an essential blood clotting protein—factor VIII or factor IX.[1,2] Approximately 18,000 Americans have hemophilia.[3] For people with hemophilia, prevention or treatment of bleeding requires the replacement of these blood-clotting factors through venous infusion. Hemophilia is considered one of the most expensive chronic health conditions to treat because the factor replacement products are very costly.[3] According to the National Hemophilia Foundation, the annual treatment cost per person ranges from $50,000 to $160,000.[3] However, according to Dr. Michael Recht, director of The Hemophilia Center at Oregon Health & Science University (OHSU) in Portland, Oregon, an active, teenage boy with severe hemophilia could require treatment costing nearly one million dollars annually (personal communication, September 12, 2012).

With the staggering costs of treating hemophilia, households including people with hemophilia may be at high risk for food insecurity—the limited or uncertain availability of nutritionally adequate or safe foods. To cover the medical expenses for a person with hemophilia, families may divert finances from other needs, including the household food budget.

National prevalence of household food insecurity has been increasing over the last decade, and many families who have never before struggled with finances are having a hard time providing enough food for everyone in the household.[4] In half of all United States (US) food-insecure households with children, adults sacrifice their own food intake to shield the children from food insecurity. However, among US households with children, 10%, or nearly 4 million households, include children who experience the effects of food insecurity, too. Figure 1 illustrates the distribution of households with children among food security status categories and the proportion of food insecure households in which children are affected by food insecurity.

Figure 1. US Households with Children by Food Security Status of Adults and Children, 2011[4]

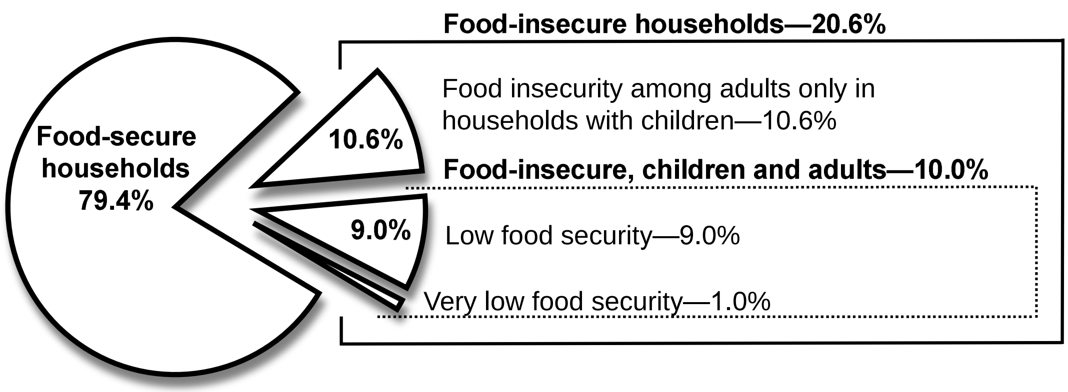


Figure adapted from Figure 2 of the USDA Economic Research Service—ERR-141—Household Food Security in the United States in 2011

Children who are food insecure are at increased risk for health disparity and developmental deficit, including overall poorer health; behavior, psychosocial, and psychological deficits; academic performance deficits; poor diet quality; and obesity.[5-12]

Living with hemophilia presents additional challenges including maintaining healthy weight and bone and joint health.[1,2] People with hemophilia may experience bleeding in their joints that makes physical activity difficult or painful. As a result, overweight and obesity are often nutritional and overall health concerns for people with hemophilia. The health and developmental consequences associated with food insecurity may be amplified for children with hemophilia.

People with hemophilia from Oregon and southwest Washington state receive care through The Hemophilia Center at OHSU, presumably for their whole life. The Hemophilia Center health care providers often have long-term health care relationships with their patients, helping patients deal with lapses in health insurance coverage and coverage gaps. The Hemophilia Center health care providers are often aware of a patient's financial needs and the long-term health care relationship aids in dealing with sensitive issues like financial struggles and food insecurity. Unlike many other health care clinics, a dietitian and a social worker are part of the multi-disciplinary health care team, providing nutrition assessment and intervention, and connecting patients to financial resources and support.

In spite of the fact that screening for food insecurity is a valuable part of comprehensive health assessment, it is currently an uncommon practice in the clinical setting.[13] The present research was designed to study households including children with hemophilia for whom prevalence and predictors of food insecurity are unknown. Because of the perceived increase risk for food insecurity among people with hemophilia, The Hemophilia Center at OHSU was uniquely open to screening for food insecurity as a part of routine clinical care. Every patient seen by the pediatric hematology providers of The Hemophilia Center was screened for household food insecurity by requesting an "Often," "Sometimes," or "Never" response to each of the following statements:

1. Within the past 12 months we worried whether our food would run out before we got money to buy more.
2. Within the past 12 months the food we bought just didn't last and we didn't have money to get more.

Specific Aims and Hypotheses

This study uses anthropometric, demographic, hemophilia-related, and food security status data representing pediatric patients of The Hemophilia Center to address two specific aims:

1. Estimate the prevalence of household food insecurity among children with hemophilia and compare to national and Oregon state prevalence rates and prevalence rates among other populations of children with special health care needs.

   Hypotheses: Prevalence of household food insecurity among children with hemophilia will be higher than national and Oregon state prevalence rates, and similar to prevalence rates among other populations of children with special health care needs.

2. Determine if household food security status is predicted by age, anthropometric, demographic, or hemophilia-related characteristics.

   Hypotheses: Food Insecurity will be predicted by older age, higher weight, height and body mass index (BMI) status, minority status, and diagnosis of severe hemophilia.

Chapter II

Background

Food Insecurity Definitions

Food insecurity is defined as the "limited or uncertain availability of nutritionally adequate and safe foods, or limited or uncertain ability to acquire food in socially acceptable ways."[14] In 2006, the United States Department of Agriculture (USDA) further characterized food insecurity as: "low food security" and "very low food security." Very low food security exists in a household when "food intake of one or more members was reduced and eating patterns were disrupted because of insufficient money and other resources for food."[4] In general, low food security is used to define the experience of reduced diet quality or variety, while very low food security defines the experience of reduced amount of food consumed, most likely in addition to reduction in quality or variety. Previous to the USDA's definitions established in 2006, very low food security was known as "hunger," a term that is still used occasionally in publications. For the purposes of this thesis, the term "food insecure" or "food insecurity" will include both low and very low levels of food security, unless otherwise specified.

Most research studies and public health reports describe food security status on the household level rather than the individual level. The USDA food security screening tool used to quantify and describe food security in the US was designed to describe the household level. Household food security status is considered a more accurate descriptor based on how food is distributed in US society.[14] A household is considered food insecure if at any time in the twelve months preceding screening the household was "uncertain of having, or unable to acquire, enough food for all household members because they had insufficient money or other resources for food."[4]

Trends in Food Insecurity

In the US, food insecurity remains a persistent problem despite an abundant food supply and continuous efforts to increase access to adequate food by many organizations, programs, and individual people.[4,15] Prevalence of household food insecurity has risen in the last decade.[4] In 2011, 14.9% of all US households experienced food insecurity. In the same year, prevalence of food insecurity in Oregon was 13.6%, a rate not considered significantly different from the national average.[4]

For households with children, the prevalence of food insecurity in 2011 was 20.6%, representing 8 million households and nearly 17 million children. Figure 2 shows the trends in food insecurity prevalence among households with children since 1998. After an increase in household food insecurity in 2008, prevalence has remained stable over the last several years. Prevalence of very low food security experienced by children has declined slightly over the past four years to the current prevalence of 1.0% of all households with children, however this small proportion actually represents 845,000 children.

Figure 2. Trends in the Prevalence of Food Insecurity and Very Low Food Security in US Households with Children, 1998-2011[4]

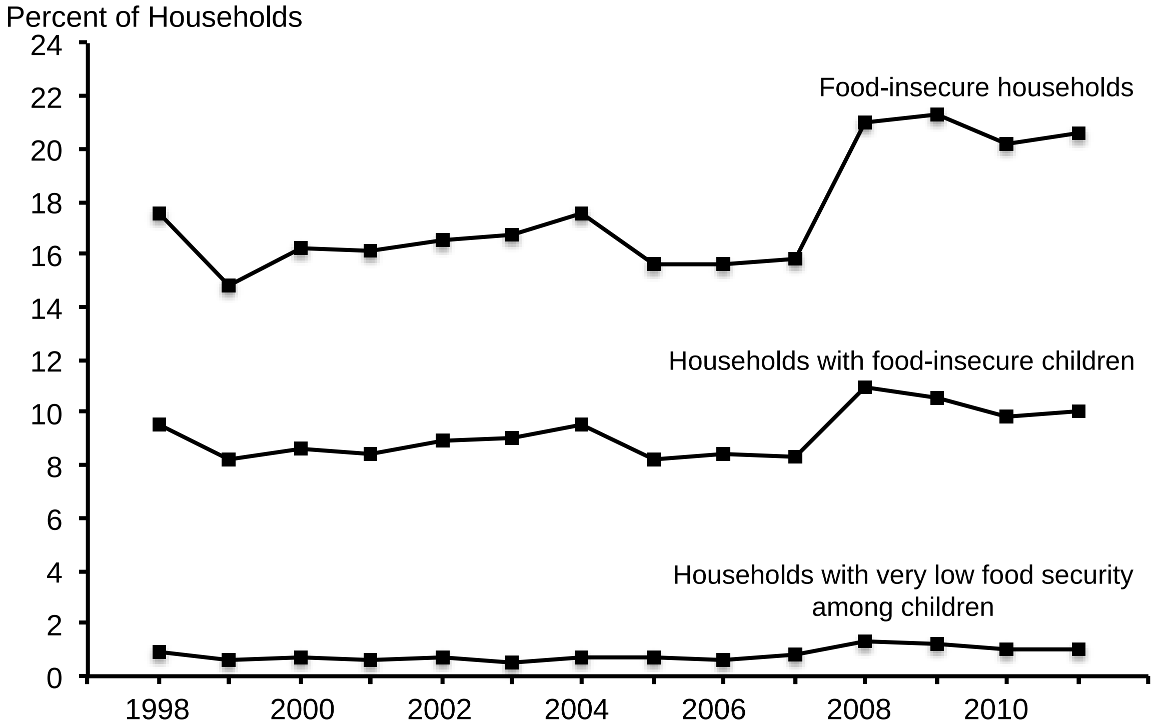


Figure adapted from Table 1B of the USDA Economic Research Service—ERR-141—Household Food Security in the United States in 2011

Assessment of Household Food Insecurity

The US continues to recognize food insecurity as an important issue and two goals of Healthy People 2020 directly address food insecurity: "Eliminate very low food security among children" and "Reduce household food insecurity and in doing so reduce hunger."[16] Food insecurity is assessed annually by the USDA as part of the Current Population Survey (CPS) conducted by the US Census Bureau.[4] These surveys contribute to a national health surveillance and monitoring system. CPS data is collected from a probability-selected sample of occupied households over the phone or in person and is therefore considered nationally representative. The CPS does not assess many health-related factors that can cause people to be at risk for food insecurity. State and regional measures of food insecurity and related information are available to further identify at-risk populations. Additional data is needed to provide information about populations not identified by existing national, state, or regional surveillance systems.

The USDA has collected information annually on food access and adequacy, food spending and sources of food assistance for the US population since 1995.[4] This data collection is made possible by the use of the 18-item Household Food Security Survey (HFSS). The HFSS was developed by the USDA and validated to assess severity of food insecurity ranging from most food secure to most severely food insecure. This survey has been administered as part of the CPS since 1995. In 1999 the National Health and Nutrition Examination Survey (NHANES) also began to administer the HFSS as part of its survey. Food insecurity data collected by NHANES and CPS have been used in many research efforts.[5-7,17,18]

USDA Core Food Security Module: Household Food Security Survey

The 18-item HFSS measures "food insecurity calculated from responses to a series of questions about conditions and behaviors that characterize households when they are having difficulty meeting basic food needs."[4] The specific questions that comprise this survey and a detailed explanation of how the surveys are scored is published in the most recent USDA food security report, Household Food Security in the US in 2011 (See Appendix A).[4] The survey asks respondents to consider any food-related incident that occurred within the previous 12 months as a result of lack of money or other resources. Because the survey specifies lack or money or other resources as the reason for food-related incidents, dieting and voluntary fasting are not assessed by this survey. The first 10 questions of the survey address food insecurity with regard to the whole household and the adults heading the household. If the household includes children, the respondents are asked to complete the remaining eight questions that address food insecurity experienced by children in the household. From this survey, households are categorized as food insecure based on the number of responses indicating food insecure conditions.

Two-Item Validated Household Food Security Screener

While the 18-item HFSS is practical for describing the severity and specific ways food insecurity may affect a household and children within the household, it is complex and time consuming to administer. A shorter, 2-item screener was developed and validated to identify food-insecure households.[19] The 2-item screener was validated by conducting the 18-item HFSS in urban medical centers among 30,098 families, of which 23% were identified as food insecure. “Often” or “sometimes” responses to HFSS questions 1 and 2 were more common among food insecure families (92.5% and 81.9%, respectively).”[19] Question 1 poses the statement: “within the past 12 months we worried whether our food would run out before we got money to buy more,” and question 2: “within the past 12 months the food we bought just didn’t last and we didn’t have money to get more.” These two questions had high sensitivity (97%) and specificity (83%) for identifying food insecurity among low income families with children.[19] By administering the 2-item screener, a health care practitioner can identify families or households at risk for food insecurity without having to administer the longer survey. If a patient is identified as food insecure by the 2-item screener, the practitioner may choose to use the more extensive HFSS or other nutrition assessment tools to further understand the effects food insecurity experienced by the patient and to provide intervention. Appendix B outlines an algorithm for screening and intervention that includes the 2-item validated screener and suggestions for further assessment and intervention such as providing information about food aid resources or referrals to a dietitian for nutrition counseling.

Predictors of Food Insecurity

Predictors of food insecurity have been identified from several national surveys including the CPS and NHANES. These surveys have shown that food insecurity disproportionately affects low-income families, single-mother-headed households, Black households, and Hispanic households.[4] Other demographic and socioeconomic predictors of household food insecurity include presence of children in the household,[4,20-22] households headed by adults with less than a 12th grade education,[22] having a disabled person in the household,[22] and the presence of housing insecurity.[21,23-29]

Adverse Effects of Food Insecurity on Child Health and Development

Five main areas of effect of food insecurity on child health and development have been identified by many studies: poor health;[5,7,8,10,11,23,26,30-35] behavior, psychosocial, and psychological effects;[8,9,12,17,36-38] academic performance;[6,8,9,39] poor diet quality;[11,40-46] and obesity.[40,42,47-56]

Poor Health

Studies that report the health effects experienced by children who are food insecure rely on information provided by home caregivers or health care providers. Health status of a child is often described by number of hospitalizations, frequency of ailments, and subjective ratings of overall health.[7,10,12,37] Alaimo et al. (1998), used data from NHANES III to study the effects of food insecurity on children's health.[18] The subjective scale of "excellent," "very good," "good," "fair," and "poor" is often used in large health surveys to assess health status. The ratings of "fair" and "poor" commonly associated with low levels of health. Studies show that children from food insecure households are more likely to be described as having "fair" and "poor" health compared to peers who are food secure.[10,11,42,48-52] A study conducted by Cook et al. found a food insecurity prevalence of 21.4% in a population of children 36 months old or younger.[7] Children who were food insecure in this population were nearly twice as likely to have a health status rating of “fair” or “poor” (adjusted odds ratio [OR] = 1.90, 95% confidence interval [CI], 1.66 –2.18) when compared to their food-secure peers. Other results of this study indicate that children who were food insecure were more likely to have been hospitalized within the first year of life when compared to their food-secure peers (adjusted OR = 1.31, 95% CI, 1.16–1.48).[7] The greater the severity of poverty combined with food insecurity, the poorer the child was rated in overall health by their home caregiver. In another study by Cook and colleagues, children from food insecure households demonstrated higher incidence of ailments, including stomach aches, headaches, and colds, a trend that was true even for children from households that experienced less severe levels of food insecurity.[57] Because of poorer health status, children who are food insecure, especially those who experience hunger, are likely to be absent from school more often (F=4.2, df=2),[37] which may contribute to the link between food insecurity and poor school performance. These findings describe just a few of the many adverse effects that food insecurity can have on the health status of a child.

Behavior, Psychosocial, and Psychological Effects

Studies describing associations between food insecurity and behavior, psychosocial, and psychological problems consistently show that children who are food insecure are more likely than their food secure peers to demonstrate problems and impairment.[8,9,12,17,36-38] These behavior problems include aggressiveness, feeling anxious, feeling depressed, or displaying attention deficit.[17] In a study by Whitaker, Phillips and Orzol (2006), mothers of 3-year-old children (n=2870) were surveyed for presence of food insecurity and behavior problems.[17] After adjusting for socio-demographic factors and maternal physical and mental health, and alcohol, drug, and tobacco use, it was found that the 3-year-old children in food insecure households, when compared to food secure peers, were twice as likely to be aggressive (OR=1.9), anxious and, or depressed (OR=2.2), inattentive or hyperactive (OR=1.9), and exhibit behavior problems (OR=2.1). Other studies show that children who are food insecure have impaired social skills,[6] and lower psychosocial functioning.[35]

The Community Childhood Hunger Identification Project used the Childhood Behavior Checklist and the Children's Global Assessment Scale to show that children who experience hunger are more likely to have lower overall function scores than their peers who are food secure.[37] Results showed that Childhood Behavior Checklist scores were significantly associated with hunger category. The rate of impairment in overall functioning was twice as high for children who experienced hunger or were at-risk for hunger (X^2=8.5, df=2).[37]

Alaimo et al. (2001), analyzed NHANES III data to describe behavioral and psychosocial functioning in children 6-11 years of age (n=3286) and adolescents 12-16 years of age (n=2063). Children and adolescents who were food insecure were nearly twice as likely to have seen a psychologist than peers who were food secure (OR=1.89 for children and OR= 1.82 for adolescents). The adolescents who were food insecure were also nearly twice as likely to have been suspended from school and to have reported trouble getting along with others (OR=1.95 and 1.74, respectively).

More recently, an Australian study by Ramsey et al. (2011) discussed that children who are food insecure are more likely to have borderline or atypical emotional problems (OR= 2.44) and to have behavior difficulties (OR= 2.35) than their peers who are food secure.[59] These studies demonstrate the many adverse effects of food insecurity on the psychosocial, psychological and behavioral aspect of children's health including emotional symptoms, conduct problems, hyperactivity, inattention, peer relationship problems, and social behavior issues.

Academic Performance

Identifying associations between food insecurity and academic performance is an integral component of many studies on children and food insecurity. In a study by Jyoti et al. (2005), children were assessed for academic performance in kindergarten and again during their third grade year.[6] Academic performance was compared to food security status. Children who experienced food insecurity for the duration between assessments had smaller gains in math and reading scores than their peers who are food secure, and those who experienced onset of food insecurity sometime between assessments had even poorer gains in reading scores than peers who were food secure.[6]

A study by Kleinman et al. (2002), reports increased math scores when children receive breakfast at school ($p<0.05$).[60] Data was collected at 97 inner city schools before the implementation of the School Breakfast Program and six months after the Program began. Before the Program, children who were at nutritional risk had a mean grade point average of 2.1, lower than the grade point average of peers with adequate nutritional intake (mean=2.8, $p<0.001$). With regard to individual subject areas (reading, math, social studies, and science), children at nutritional risk had a statistically significant difference of one-half to one full letter grade lower than nutritionally adequate peers.[60] After six months of the School Breakfast Program, nutritional risk and academic performance were reevaluated. Thirty-two percent of the children that demonstrated participation in School Breakfast Program also demonstrated improved nutritional status and significantly fewer days absent from school (mean= 4.4 fewer days absent, $p<0.01$).

There are many other studies that aim to test associations between food security and academic performance that were unable to do so due to inadequate sample sizes and multiple confounding factors. Despite these limitations, the evidence suggests a trend of decreased school performance with increased food insecurity and is reason enough for continued research consideration.

The body of research describing poor health outcomes and behavior and psychological problems related to food insecurity can contribute to the understanding of the effect of food insecurity on academic performance. Often poor health may remove a child from the school environment, potentially affecting academic performance independent of ability to perform academically. Also, behavior and psychological problems that present in the classroom can contribute to reduced academic performance. It is possible for a child who is food insecure to have poor academic performance independently of poor health and behavior and psychological problems. In a longitudinal study of household food insecurity and associations with adverse outcomes in children and adolescents, Frongillo et al. (2006) identified strong evidence that use of the Supplemental Nutrition Assistance Program (SNAP), formerly known as the Food Stamp Program, can directly improve academic performance.[39] This academic improvement was measured as a 3 point greater increase in standardized math and reading scores between kindergarten and third grade when the student maintained participation in the Food Stamp Program.

Diet Quality

In the US food environment of easily accessible, poor quality, cheap food, it is common for the average US citizen to eat a diet lacking in essential nutrients and balanced in energy sources.[41,44-46,60] Compounding this problem with inadequate financial resources deepens the burden of eating a healthy diet.[40] Nutrient deficiencies experienced, particularly over extended periods of time, can have adverse effects on a child's health and development.[8,30,31,45,59,61] Conversely, excessive intake of nutrients like saturated fat, cholesterol, and sugar from cheaper, processed foods may adversely affect a child who is food insecure into adulthood by increasing their risk of chronic conditions such as cardiovascular disease or earlier onset of type 2 diabetes mellitus.[32] Accurately assessing dietary intake is a complicated and time-consuming process that is difficult and costly to perform on a large scale. Studies aiming to identify effects of food insecurity on diet quality use data from large surveys that have limited data on reported dietary intakes. Casey et al. (2001) studied a sample of over five-thousand children for whom they had two 24-hour dietary recalls, food security data, and household income level.[11] Low income, children who were food insecure had significantly lower total energy intakes (P=0.05), and higher cholesterol (P=0.02) intakes compared to higher income peers who were food secure. No other significant nutritional deficits were observed when analyzing the micronutrient consumption of children who were food insecure compared to those who were food secure.

A Canadian study had access to two 24-hour dietary recalls and household food security data for 2162 children and adolescents, of whom 12.8% were food insecure.[41] Analyses of dietary patterns comparing children who were from food secure versus food insecure households found no significant nutritional inadequacies among children from food insecure households. Among adolescents, higher prevalence of nutrient inadequacies, including protein, vitamin A, thiamin, riboflavin, vitamin B-6, folate, vitamin B-12, magnesium, phosphorus, and zinc, were evident for food insecure adolescents.[41]

Obesity

Whether obesity and food insecurity are associated is a topic of persistent debate. There is evidence that overweight and obesity are associated with food security status.[47,48,53,54,62] Some studies show no significant associations, or inconsistencies in association between food insecurity and overweight between categories of age, gender, or race and ethnicity.[6,10,30,55] Household income, age, race and ethnicity, experience of hunger, content of diet, geographic location, participation in physical activity are all confounding variables that make it difficult to characterize associations between food security status and weight status.

Casey et al. (2006), evaluated BMI data from NHANES surveys of children aged 3-17 (n=6995). Researchers analyzed both the overweight category (BMI >95%ile) and the at-risk for overweight category (BMI >85%ile). Results suggest that for children from households that were food insecure, household food insecurity (but not child food insecurity) was associated with overweight and at-risk for overweight in children 12-17 years of age, girls, and children from household with income >4 times poverty level. When analyzing data for children who have experienced food insecurity, childhood food insecurity is associated with a greater likelihood of overweight or at-risk for overweight in children 3-5 years old, boys, and Mexican-American children, in addition to the previously identified groups.[53] These results were also supported when researchers analyzed age and gender categories separately, though not all results in each category were statistically significant.[53] In a study of preschoolers (n=1514), children were nearly three and a half times more likely to be overweight if they lived in food insecure homes (OR = 3.4). These results were supported even after adjusting for variables such as birth weight, parents' weight status, income, and education.[54]

In contrast, Rose and Bodor (2006) analyzed a data set from the Early Childhood Longitudinal Study, Kindergarten Cohort, of children who were assessed during kindergarten and again in first grade (n=12890). The 18-item HFSS was administered to assess food security status. Although there were no associations between food insecurity and child overweight status, after adjusting for confounders, an odds ratio of 0.80 suggested that children from food insecure households were 20% less likely to be overweight than their peers who are food secure.[55]

Food Security Screening and Intervention at the Primary Care Level

Identifying food insecurity in patients in the primary care setting is an underutilized practice.[13,63,64] Primary health care providers have unique, individualized access to their patients and often the patient's home caregivers. If primary health care providers assessed food security status as part of their routine care, they may be able to better understand any existing health and development issues related to food insecurity, or take the opportunity to assess risk of health and development issues.

In recent years, the proportion of families using food assistance programs and emergency food sources for the first time has increased.[4] However, one third of individuals eligible for government food aid programs do not participate, leaving them with less food resource than they could have.[65,66] Assessing food insecurity during a child's annual wellness exam or illness-related visits may be the first and possibly the only opportunity to identify a child and household that are food insecure. Families with recent onset of food insecurity may not know of resources or food assistance programs for which they may be eligible or how to access those resources.[19]

When food insecurity is identified, an assessment of currently accessed food aid resources should also be conducted. This will help the health care provider identify any additional programs for which the household may be eligible and provide referral to additional resources. Government and community resources may be available to help alleviate food insecurity. Government resources include programs such as the Supplemental Nutrition Assistance Program (SNAP); Temporary Aid for Needy Families

(TANF); Supplemental Nutrition Program for Women Infants and Children (WIC); and school meal programs including the School Breakfast Program (SBP), National School Lunch Program (NSLP), and Summer Food Service Program (SFSP), among others. Other community resources may include local food banks and pantries, emergency food box programs, food gleaning programs, and congregate meal sites or soup kitchens.

Primary health care providers have many reasons for not asking about food insecurity, including time constraints, lack of knowledge about food insecurity or local resources, or that it is not a part of institutional practice.[63] However current research and public health efforts have led to the development of simple tools to screen for food insecurity.[19] The Childhood Hunger Coalition is an Oregon-based, multi-disciplinary group of healthcare and advocacy professionals dedicated to elimination the public health impacts of childhood hunger. In 2009, the Childhood Hunger Coalition conducted a statewide assessment of food security screening practices in the primary care setting.[64] The results of this assessment showed that most pediatric providers are willing to address household food security status in clinic (78%) and are willing to use standardized screening questions to identify risk for food insecurity (89%).[63] These statewide findings are consistent with the same assessment conducted in 2008 in the Portland, Oregon metropolitan area.[64]

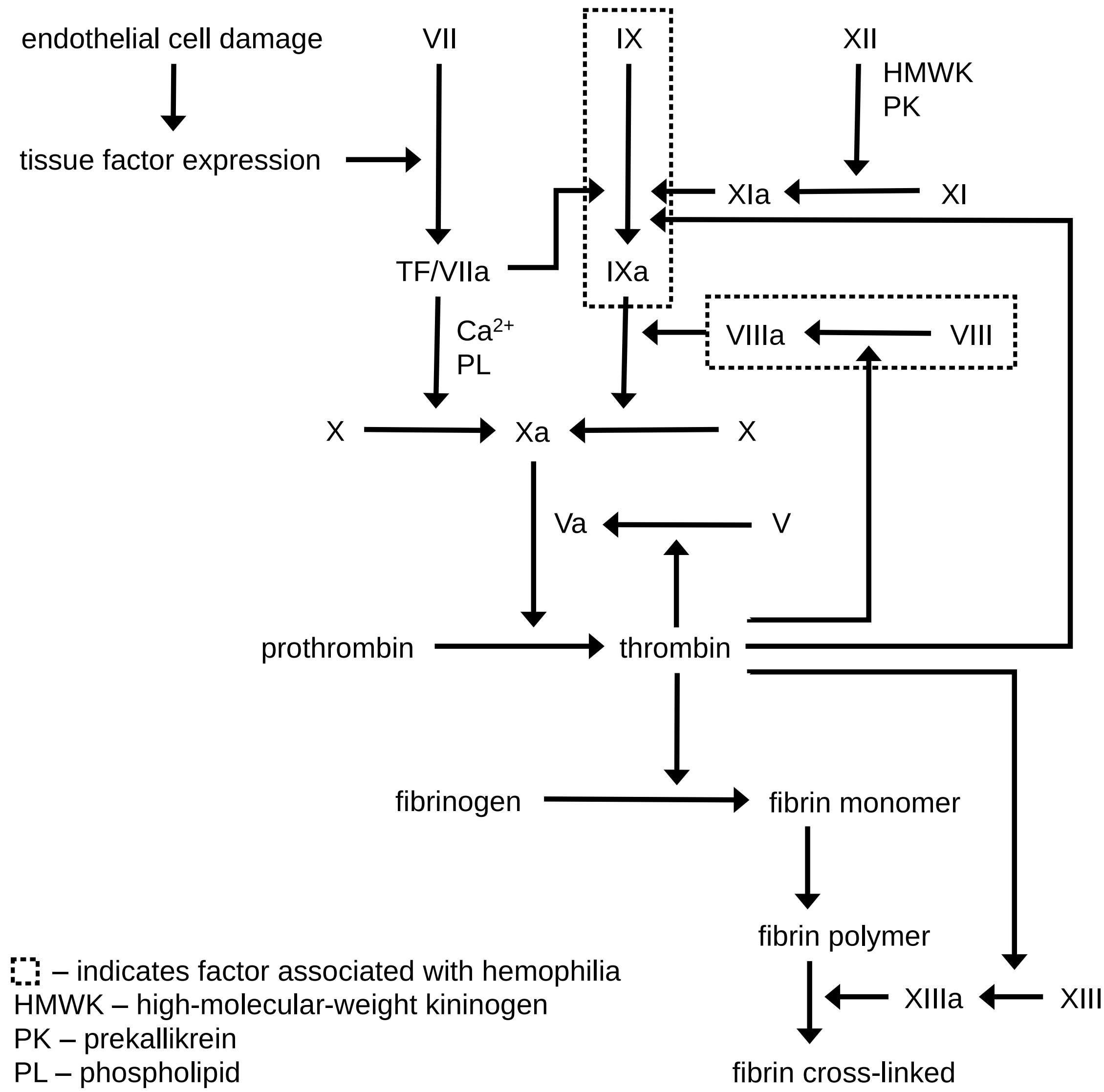
In partnership with the Oregon Food Bank, the Childhood Hunger Coalition has conducted parent focus groups to assess their experiences with food insecurity and their willingness to address food insecurity with their care providers. The focus groups revealed that parents were willing to address hunger and food access with their care providers when a trusting relationship was established.[63] Other sources confirm that parents are willing to address food insecurity with their care providers.[19]

Screening for food insecurity should become an important part of routine well-child care. Implementation of food security screening could facilitate referrals to new or additional assistance programs and offer opportunity for adequate follow-up with families.[8] Using the primary care setting as an opportunity to identify households at risk for food insecurity and to intervene could lower the prevalence of food insecurity. The procedure for screening could be as simple as adding the 2-item screen to the list of health assessment questions asked by primary care providers. It would be helpful for primary care providers to have a basic understanding of food aid resources available in the community and eligibility requirements for each resource. Resource lists have been developed at Oregon Health & Science University in cooperation with Oregon State University Extension Services. These resource lists have been integrated into the electronic medical record system and allow health care providers to give patients individualized, printed resource lists. Referrals to other health care professionals including registered dietitians and licensed social workers are also helpful in connecting patients to the nutrition care and food resources they may need.

Overview of Hemophilia

Hemophilia is the congenital deficiency of an essential blood clotting protein—factor VIII or factor IX.[1,2] Deficiency in factor VIII is known as hemophilia type A and deficiency in factor IX is known as hemophilia type B. Deficiency in a clotting factor means that the complex cascade of reactions to recognize and stop internal or external bleeding by forming a firm clot is very inefficient or cannot be completed. Figure 3 illustrates the cascade of interactions between clotting factors required for the formation of a clot.

Figure 3. Coagulation Cascade



Courtesy of M. Recht, MD, PhD

In 2012, there were approximately 18,000 Americans living with hemophilia,[3] of which 80% had factor VIII deficiency or hemophilia A.[1,2] The risk of hemophilia is the same for all races and ethnicities.[3] Screening for hemophilia is not conducted as part of the normal newborn screening profile. However, infants born to mothers who are known to be carriers of the condition are tested for factor VIII or IX deficiency at the time of birth. For male infants born without a family history of hemophilia, diagnosis typically occurs after circumcision when bleeding from the wound does not stop (Michael Recht, personal communication, September 12, 2012). For infants who are not circumcised, diagnosis may occur within the first few years of life when atypical bruising or bleeding is noticed (Michael Recht, personal communication, September 12, 2012). Bleeding patterns, signs and symptoms and method of treatment are the same for hemophilia type A and type B, but the treatment products used to stop bleeding are different.[1] For the purpose of this thesis, the term "hemophilia" will be used to describe type A and type B collectively unless otherwise specified.

Genetics and Inheritance of Hemophilia

The deficiency in clotting factor VIII and XI is cause by a mutation of a gene on the X-chromosome that limits or prevents the production factor VIII or IX.[1,2] Hemophilia is typically inherited as an X-linked recessive trait. As 30% of newly diagnosed children can be attributed to spontaneous gene mutation with no previous family history. Hemophilia can be caused by a variety of genetic mutations on the X-chromosome. Some mutations produce dysfunctional forms of the clotting factor protein and the other mutations produce insufficient amounts of clotting factor protein. Because of the variety in gene mutations, hemophilia is diagnosed and characterized by measuring the clotting factor protein activity, rather than genetic testing. Factor protein activity can be categorized as mild, moderate, or severe. People with mild hemophilia have 5-30% of normal circulating levels of clotting factor. People with moderate hemophilia have 1-5% of normal circulating levels of clotting factor and people with severe hemophilia have less than 1% of normal circulating levels of clotting factor.[1,2]

A male child receives an X-chromosome from his mother and a Y-chromosome from his father. If the X-chromosome has the mutated gene, he will have hemophilia. If a female child receives a mutated X-chromosome from one of her parents, but receives a normal X-chromosome from the other parent, the normal X-chromosome will dominate and she will be able to produce sufficient amounts of clotting factor. She will not have hemophilia, but will be a carrier of the hemophilia trait. Some females who are carriers have low levels of clotting factor and can experience symptoms. Among these females, there is a trend to self-identify as having hemophilia (Michael Recht, personal communication, September 12, 2012). The majority of patients of hemophilia treatment centers are male.[1-3]

Symptoms of Hemophilia

People living with hemophilia are at high risk for experiencing spontaneous bleeding episodes. [1,2] The frequency and severity of these episodes is related to the severity of clotting factor deficiency. Twenty-five percent of people with hemophilia have mild hemophilia and may only experience abnormal bleeding in the event of major trauma or surgery,[1,2] Sometimes people with mild hemophilia are not diagnosed until adolescence or adulthood when a serious injury, like breaking a bone or being in a car accident, or surgery, such as removal of the appendix or wisdom teeth extraction, causes uncontrolled bleeding (Michael Recht, personal communication, September 12, 2012). People with moderate hemophilia, about 15% of cases, may experience spontaneous bleeding episodes and uncontrolled bleeding is likely after an injury. Sixty percent of people with hemophilia have a severe form and are likely to experience frequent spontaneous bleeding episodes from normal physical activity, including internal bleeding within joints and muscles, and uncontrolled bleeding from minor internal or external injury.[1-3]

Bleeding in bone joints and muscles, if not clotted and cleared, can lead to blood pooling, joint or muscle damage, discomfort with use of the joint, and loss of range of motion. Perhaps the most life-threatening incidents for people living with hemophilia are those causing bleeding in the brain, internal bleeding, or from serious external wounds.[1,2]

People living with or caring for someone with hemophilia must take special precautions when participating in usual or common activities. Surgeries or even preventative dental care must be performed according to plans for management of bleeding. Some parents of children with hemophilia may feel overly cautious and protective, or restrict participation in physical activity and normal play activities. However, education from providers can include ways to prepare a home environment for the safety of a child, or planning for a child's safe participation in sports and other physical activity. For some people with hemophilia, the experience of bleeding in the joints and muscles is uncomfortable enough to discourage a healthy, active lifestyle, or participation in certain types of employment.[1,3] However, appropriate treatment of hemophilia can allow a person with hemophilia to live a long, healthy, and active life.[1-3]

Treatment of Hemophilia

The most effective treatment of hemophilia is replacement of clotting factor.[1,2] Other treatments include patient and family or caregiver education for safety and care management, therapies to help alleviate and heal the symptoms after bleeding episodes, and therapies to facilitate appropriate physical, emotional, and social development.[1,2]

Recombinant (synthetically produced) or plasma-derived (from donated blood) factor concentrates are commonly referred to by the general term “factor” (Michael Recht, personal communication, September 12, 2012). Factor is exogenously administered through direct infusion into the veins. For some patients, the most effective method of treatment is to administer doses of the clotting factor several times each week so that it is always circulating in the body and available as needed. This form of clotting factor replacement therapy is called “prophylaxis”. Some patients receive doses of clotting factor only when they are having a bleeding episode. This form of clotting factor replacement therapy is called “on-demand.”[1,2,67] Factor is also administered in preparation for special physical activities or medical procedures that may cause bleeding. This form of treatment is known as situational or secondary prophylaxis.

Administration of clotting factor can cause an immune response and eventual immunity to the factor product. The body’s immune system recognizes the clotting factor as foreign or “not of self” and develops immunity so that future administration of the clotting factor product may not provide the necessary clot-forming properties.[1,2] There are multiple clotting factor products available and each patient’s need for and responses to specific factor products are evaluated by the hemophilia care providers, family, and patient on an individual basis (Michael Recht, personal communication, September 12, 2012).

Quality of Life and Impact of Living with Hemophilia

Living with hemophilia has many effects on quality of life, experience of pain, mobility issues, special physical development needs, as well as emotional, social, and, or financial stress. Physical therapists, occupational therapists, psychologists, and social workers are often involved in the provision of care for patients with hemophilia and their family or care providers.[68]

Physical Impact

A common symptom of moderate and severe hemophilia is bleeding into joints and muscles due to normal body movements. When blood pools in joints, it causes severe pain and swelling, and a likely cessation or limitation of activity. Current recommendations for treatment of hemophilia include promotion of physical activity with appropriate clotting factor replacement therapy. However, if the therapy is unavailable or ineffective, a person with hemophilia may be discouraged from participating in normal physical activity.[1,2]

Factor replacement therapies have extended the life expectancy of people living with hemophilia equal to that of the general population such that people with and without hemophilia are now similarly susceptible to overweight and obesity and comorbid chronic diseases. While somewhat inconsistent, evidence suggests that overweight and obesity rates in the population with hemophilia are similar to the general population. However, due to the effect of overweight and obesity on joint health, people with hemophilia may be more susceptible to joint arthropathies commonly experienced by people who are overweight or obese.[1,2]

Financial Impact

As previously mentioned, treatment of hemophilia is often costly. The clotting factor medications are expensive and variably covered by patient insurance. In addition to routine primary care provider appointments, people with hemophilia may require additional appointments to treat bleeding episodes, and appointments with other health care specialists for physical therapy or mental health care. Otherwise routine dental, surgical or other medical procedures may require additional preparation appointments or medical specialists, incurring more frequent and higher fees or co-payments. As with any population, a proportion of individuals with hemophilia have inadequate or gaps in health insurance coverage. For families covering medical expenses out-of-pocket or paying numerous co-payments, medical costs may require financial sacrifice in other areas of life.[2,67]

Food Insecurity Among Households Including Children with Hemophilia

Due to the high cost of living with hemophilia, one area that families may feel forced to sacrifice financially is in their food spending. As the amount of money spent on food decreases, families may be at greater risk for food insecurity. Currently there is no published data on the prevalence or predictors of food insecurity in children with hemophilia.

Chapter III

Methods

Study Design

A retrospective, cross-sectional design was used to analyze data collected between May 25, 2012 and January 31, 2013. This data was used to determine the prevalence of household food insecurity in the sample and to determine relationships between food security status and anthropometric, demographic, and hemophilia-related characteristics. The study protocol was exempt from obtaining participant consent because all study variables were collected as part of routine clinical care. The study protocol was approved by the Oregon Health & Science University Institutional Review Board.

Sample and Setting

The participants in this study were pediatric patients with hemophilia between 0 and 17 years of age who attended their annual comprehensive appointment at The Hemophilia Center at OHSU and patients seen by the hemophilia team that travelled to provide comprehensive clinics outside the Portland metropolitan area. Eligible participants were from any part of Oregon or southern Washington state, though patient residence was not collected for this study.

Inclusion and Exclusion Criteria

The main inclusion criterion was that the participant had a diagnosis of Hemophilia A or B. Patients of The Hemophilia Center who were older than 17 years of age at the time of their comprehensive appointment were excluded. Patients were also excluded from the study if a younger sibling was eligible for inclusion. Rationale for including the younger sibling and excluding the elder sibling comes from the study that validated the 2-item food security screener.[19] Hager et. al. (2010) specifically validated the screening tool for use in screening households with children less than 2 years of age.

Anthropometric, demographic and food security screening data were available for all participants and therefore no participants were excluded due to missing data. Information about factor infusion was available dependent on the type of treatment prescribed and whether the participant ordered factor directly from The Hemophilia Center. Analyses using these data points were limited, and participants with incomplete data were excluded.

Data Collection and Management

All data were obtained from the Oregon Health & Science University Hospital & Clinics EpicCare® Electronic Medical Record. Data was stored in an electronic REDCap® database created specifically for this study. In final form, the data was exported, without identifiers to a Microsoft® Excel file and imported to a Statistical Package for Social Sciences ® Version 21 (Chicago, IL) database for all analyses. Z-scores for anthropometric measurements were calculated by comparing measurements to Centers for Disease Control and Prevention (CDC) reference growth data using Epi-Info® Version 7 (Atlanta, GA).

Data for this study were collected as part of routine clinical care from patients and accompanying family members who attended an annual comprehensive appointment at The Hemophilia Center. This appointment was a single encounter with the study participant and all anthropometric measurements and food security screening data were representative of the participant and household on the date of the comprehensive appointment. The database form that was used to collect data can be found in Appendix B.

Anthropometric Measurements

Height of the participant was measured and recorded to the nearest 0.1 centimeter (cm) by the clinic staff using a Holtain Limited Harpenden wall-mounted stadiometer (Crymych, United Kingdom). Weight of the participant was measured and recorded to the nearest 0.01 kilogram (kg) by the clinic staff using the A-1 ABM scale Model TR-1-NK by Tara Systems (Escondido, California). If the participant was too young to stand for the measurements, a Scale-tronix Pediatric/Infant Scale Model 4802D (Carol Stream, Illinois) was used to measure weight and a Hopkins Medical Products standard recumbent measuring board (Baltimore, MD) was used to measure length. For each participant under two years of age, a weight-for-length percentile value was calculated using weight and length measurements and comparing the values to CDC growth charts specific to age and sex. For participants over two years of age, BMI was calculated as weight in kilograms divided by height in meters squared. Age, sex, weight, and height values were entered in to Epi-Info® version 7 to calculate Z-scores. Z-scores are calculated by subtracting the mean value for the reference population from the observed value and dividing by the standard deviation of the population.

Demographic Data

Demographic data collected from the electronic medical record included age at time of encounter, gender, race, ethnicity, language spoken at home, and type of health insurance. It was also recorded if the patient had a sibling with hemophilia and whether or not that sibling was included in the study.

Hemophilia Data

Medical data collected from the electronic medical record included hemophilia diagnosis (type A or B), severity (mild, moderate, or severe), and number of bleeding episodes in the past year. Factor prescription, infusion schedule, and total units ordered in the 2012 calendar year were recorded when available. Factor prescription was recorded for all participants following “on demand” or “prophylaxis” treatment regimens. For participants following a “prophylaxis” regimen, the schedule of infusion was also recorded. For participants following a “prophylaxis” regimen, a normalized factor units per kilogram of body weight per year was calculated based on their prescription. Normalized factor units per kilogram of body weight per year is the standard measurement used to compare severity of hemophilia and patient factor requirement. For participants who ordered their factor from The Hemophilia Center Factor Program during 2012, total units ordered was recorded and used to calculate a normalized value for the actual factor units ordered. Comparing these two normalized values allowed for calculation of the percent difference between the prescribed and the actual use of factor. However, significance of the normalized value for ordered factor and percent difference calculated is limited by the lack of recorded history of reasons for ordering more or less factor than prescribed.

Food Security Status Data

The validated 2-item food security screener results and a list of currently used food resources were also collected as part of routine clinical care. Due to the sensitive nature of the food security data, practitioners who were familiar to the patients and families administered the food security screener and collected a list of food aid resources used. These practitioners included the physician and the social worker who hold permanent positions at The Hemophilia Center. To administer the 2-item food security screener, the physician asked the accompanying family members from the same household to respond to the following two statements by answering "often," "sometimes," or "never": "Within the past 12 months we worried whether our food would run out before we got money to buy more," and "Within the past 12 months the food we bought just didn't last and we didn't have money to get more." An "often" or "sometimes response to either, or both statements identified a food insecure household. There were no participants who were unwilling to provide responses or who were unsure what response to provide. A list of commonly used food aid resources was included in the study database form (See Appendix C). If any provider note from the study encounter indicated use of a specific resource, it was collected in the study database.

Statistical Analyses

Data analyses included descriptive statistics of the sample including demographic, anthropometric, food security screening, and hemophilia-related data. Mean, standard deviation, minimum and maximum values, and 95% confidence intervals were reported to describe the age and anthropometric measurements of the sample and subsets, including food secure and insecure, mild-to-moderate and severe hemophilia, children with public insurance, and children of minority race or ethnicity.
These subsets were chosen for analyses because they are hypothesized to have significant relationships between anthropometric, demographic, hemophilia-related characteristics and food security status.

Proportions were used to describe the categories of gender, race, ethnicity, health insurance type, hemophilia type and severity, and treatment type for the sample and several subsets. Proportions and 95% confidence intervals were also used to describe a main outcome of prevalence of food insecurity in the study population and subsets.

T-tests were used to compare the difference in means between children with and without food insecurity in the sample and subsets. Mean difference and 95% confidence intervals for age, weight Z-scores, height Z-scores, and BMI Z-scores were tested and P-values < 0.05 were considered statistically significant. Differences in means were calculated by subtracting the food insecure mean from the food secure mean.

Logistic regression models and were used to determine relationships between age, weight Z-score, height Z-score, BMI Z-score and the outcome of food security status. Odds ratios and 95% confidence intervals for the odds ratio were calculated to represent the odds of being food insecure per one-year increase in age or one (1.0) unit increase in Z-score. P-values < 0.05 were considered statistically significant.

Chi-Square analyses were used to determine the difference in proportions of race, ethnicity, health insurance type, hemophilia severity, and treatment type between food security status groups in the sample and subsets. Fisher's Exact Test P-values < 0.05 were considered statistically significant.

Chapter IV

Results

Sample Characteristics

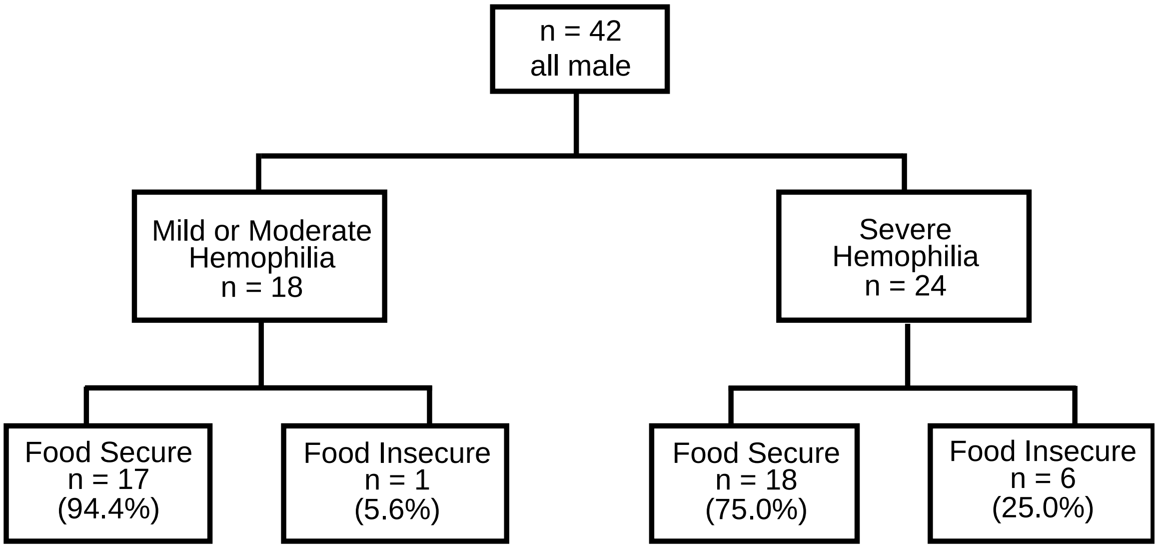
All 42 participants were male. Age and anthropometric characteristics of the sample and subsets, are presented in Table 1. The mean age of the study sample was 9.6 years with a range of 0.1 to 18 years. The mean BMI Z-score of the sample was 0.6. In Table 1 and Figure 5, weight-for-height Z-scores were used in place of BMI Z-scores for participants under the age of 2 years, as BMI Z-score reference data is not available for this age group.

The majority of participants were white (n=39, 92.9%) and not Hispanic or Latino (n=36, 85.7%). Due to the small minority representation, race and ethnicity were not analyzed as individual subsets, rather any child identified by a minority race and, or ethnicity were combined to form a subset (n=9). Only two participants were primarily Spanish-speaking (all others were English-speaking) and due to this small proportion, language spoken was not analyzed.

The majority of participants had hemophilia type A (n=39, 92.9%). Due to the small proportion of participants with hemophilia B and the similarity between effects and treatments of both types, hemophilia type A and B were not analyzed individually for subset characteristics.

More than half of the sample had severe hemophilia (n=24, 57.1%, Type A or B). The proportions of participants within each severity category following a prophylactic, on demand, or no factor treatment regimen are shown in Table 2. Nearly all of the participants following a prophylactic treatment regimen had severe hemophilia.

Figure 4. Distribution of Participants by Severity of Hemophilia and Food Security Status.



Because hemophilia is a rare condition and the study sample represents a majority of children with hemophilia from Oregon and southwest Washington, some data points describing minorities, small sample proportions, or outlying data are not reported or analyzed in greater detail for the protection of patient identity and health information.

Table 1. Sample Characteristics: Age and Anthropometric Measurements

	Sample	Food Insecure	Food Secure	Severe Hemophilia	Mild & Mod Hemophilia[a]	Public Insurance	Minority Race/Ethn[b]
Sample Size, n	42	7	35	24	18	17	9
Age (years) Mean ± SD	9.6 ± 5.4	11.0 ± 4.3	9.3 ± 5.6	10.2 ± 5.0	8.8 ± 5.9	8.5 ± 6.0	10.7 ± 5.1
(min, max)	(0.1, 17.9)	(5.4, 15.9)	(0.1, 17.9)	(0.3, 17.0)	(0.1, 16.2)	(0.1, 15.9)	(0.1, 15.5)
95% CI	(7.9, 11.2)	(7.8, 14.2)	(7.4, 11.1)	(8.1, 12.2)	(6.0, 11.5)	(5.6, 11.3)	(7.3, 14.0)
Weight Z-Score Mean ± SD	0.6 ± 1.4	1.1 ± 1.2	0.5 ± 1.5	0.5 ± 1.3	0.8 ± 1.6	0.6 ± 1.3	0.9 ± 1.3
(min, max)	(-2.2, 3.9)	(-0.4, 3.3)	(-2.2, 3.9)	(-1.7, 3.9)	(-2.2, 3.3)	(-1.7, 3.3)	(-1.7, 2.7)
95% CI	(0.2, 1.1)	(0.2, 2.0)	(0.1, 1.0)	(0.0, 1.0)	(0.1, 1.5)	(-0.1, 1.2)	(0.0, 1.7)
Height Z-Score Mean ± SD	0.3 ± 1.1	0.6 ± 0.8	0.2 ± 1.1	0.3 ± 1.1	0.3 ± 1.0	0.0 ± 1.0	0.5 ± 1.3
(min, max)	(-2.0, 2.4)	(-0.4, 1.6)	(-2.0, 2.4)	(-2.0, 2.2)	(-1.6, 2.4)	(-2.0, 1.6)	(-2.0, 2.4)
95% CI	(-0.0, 0.6)	(0.0, 1.2)	(-0.1, 0.6)	(-0.2, 0.7)	(-0.2, 0.8)	(-0.5, 0.5)	(-0.4, 1.4)
BMIZ-Score[c] Mean ± SD	0.6 ± 1.3	0.8 ± 1.4	0.5 ± 1.3	0.4 ± 1.3	0.7 ± 1.4	0.6 ± 1.2	0.8 ± 1.3
(min, max)	(-2.5, 3.6)	(-1.3, 2.9)	(-2.5, 3.6)	(-1.7, 3.6)	(-2.5, 2.9)	(-1.3, 2.9)	(-1.3, 2.2)
95% CI	(0.2, 1.0)	(-0.2, 1.8)	(0.1, 0.9)	(-0.1, 1.0)	(0.1, 1.4)	(0.0, 1.2)	(-0.1, 1.6)

[a]Subset includes all children with mild or moderate hemophilia
[b]Subset includes all children identified as a minority race and, or ethnicity
[c]Weight-for-Height Z-scores were used instead of BMI Z-scores for children < 2 years

SD - Standard Deviation
CI - Confidence Interval
BMI - Body Mass Index

Table 2. Food Security Status, Demographic and Hemophilia-related Sample Characteristics

	Sample	Food Insecure	Food Secure	Severe Hemophilia	Mild & Mod Hemophilia[a]	Public Insurance	Minority Race/Ethn[b]
Sample Size, n	42	7	35	24	18	17	9
Food Security, % Food Insecure	16.7 (7)[c]	100 (7)	0 (0)	25.0 (6)	5.6 (1)	29.4 (5)	44.4 (4)
95% CI	(5.4, 28.0)			(7.7, 42.3)	(0.0, 16.2)	(7.7, 51.1)	(11.9, 76.9)
Race, % White	92.9 (39)	71.4 (5)	97.1 (34)	91.7 (22)	94.4 (17)	82.4 (14)	0 (0)
Ethnicity, % Hispanic or Latino	14.3 (6)	28.6 (2)	11.4 (4)	20.8 (5)	5.6 (1)	23.5 (4)	66.7 (6)
Insurance Type, % Public	40.5 (17)	71.4 (5)	34.3 (12)	45.8 (11)	33.3 (6)	100 (17)	77.8 (7)
Hemophilia Type, % A	92.9 (39)	85.7 (6)	94.3 (33)	91.7 (22)	94.4 (17)	94.1 (16)	88.9 (8)
Hemophilia Severity, % Severe	57.1 (24)	85.7 (6)	51.4 (18)	100 (24)	0 (0)	64.7 (11)	77.8 (7)
Treatment Type, % Prophylaxis	47.6 (20)	71.4 (5)	42.9 (15)	79.2 (19)	5.6 (1)	52.9 (9)	55.6 (5)

[a]Subset includes all children with mild or moderate hemophilia
[b]Subset includes all children identified as a minority race and or ethnicity
[c]Values in parentheses are (n)

CI - Confidence Interval

Table 3. Difference in Means of Children With and Without Food Insecurity[a,b,c]

	Sample	Severe Hemophilia	Minority Race or Ethnicity	Public Insurance
Age	-1.7 (-6.2, 2.9)	0.0 (-5.0, 5.1)	0.5 (-8.2, 9.1)	-4.3 (-10.9, 2.4)
Weight Z-Score	-0.6 (-1.8, 0.6)	-0.3 (-1.6, 1.0)	-0.2 (-2.4, 2.0)	-1.3 (-2.6, 0.0)
Height Z-Score	-0.4 (-1.2, 0.5)	-0.7 (-1.7, 0.4)	-1.1 (-3.1, 0.9)	-1.1 (-2.1, 0.0)
BMI Z-Score	-0.3 (-1.4, 0.8)	0.0 (-1.3, 1.3)	0.5 (-1.6, 2.5)	-0.6 (-2.0, 0.8)

[a]All values are Mean Difference (95% Confidence Interval of the Mean Difference)
[b]Mean Differences reported as Food Secure - Food Insecure
[c]All P-Values > 0.05

Table 4. Effects of Age and Anthropometric Measurements on the Odds of being Food Insecure[a,b,c]

	Sample	Severe Hemophilia	Minority Race or Ethnicity	Public Insurance
Age	1.1 (0.9, 1.3)	1.0 (0.8, 1.2)	1.0 (0.8, 1.3)	0.9 (0.7, 1.1)
Weight Z-Score	1.3 (0.7, 2.4)	0.8 (0.4, 1.7)	0.9 (0.3, 2.5)	0.3 (0.1, 1.2)
Height Z-Score	1.4 (0.6, 3.2)	0.5 (0.2, 1.4)	0.4 (0.1, 1.8)	0.1 (0.0, 1.1)
BMI Z-Score	1.2 (0.6, 2,2)	1.0 (0.5, 2.1)	1.4 (0.4, 4.3)	0.7 (0.3, 1.7)

[a]All values are Odds Ratio (Wald 95% Confidence Interval for the Odds Ratio)
[b]Odds of being food insecure with each 1.0 year or Z-score unit increase
[c]All P-Values > 0.05

Table 5. Significance of Difference in Proportions of Demographic and Hemophilia-related Characteristics Between Food Secure and Food Insecure Groups[a,b]

	Sample	Severe Hemophilia	Minority Race or Ethnicity	Public Insurance
Race	0.07[c]	0.05[c]	0.52	0.19
Ethnicity	0.26	0.57	0.52	0.54
Insurance	0.10	0.36	0.44	-
Severity	0.21	-	0.44	0.60
Treatment Type	0.19	0.11	0.35	0.86

[a]All values are P-values derived from Fisher's Exact Test
[b]All tests had at least one cell with an expected count < 5
[c]Significance limited by multiple cells with an expected count < 5

Prevalence of Household Food Insecurity

Prevalence of household food insecurity in the sample was 16.7% (95% CI, 5.4-28.0%). Household food insecurity was rare among those with mild or moderate hemophilia (n=18, 5.6%; 95% CI, 0.0-16.2%) and concentrated among those with severe disease (n=24, 25.0%; 95% CI, 7.7-42.3%). In the small subset of participants identified as a minority race or ethnicity, prevalence of household food insecurity was high (n=9, 44.4%; 95% CI, 11.9-76.9%).

Age of Children with and without Food Insecurity

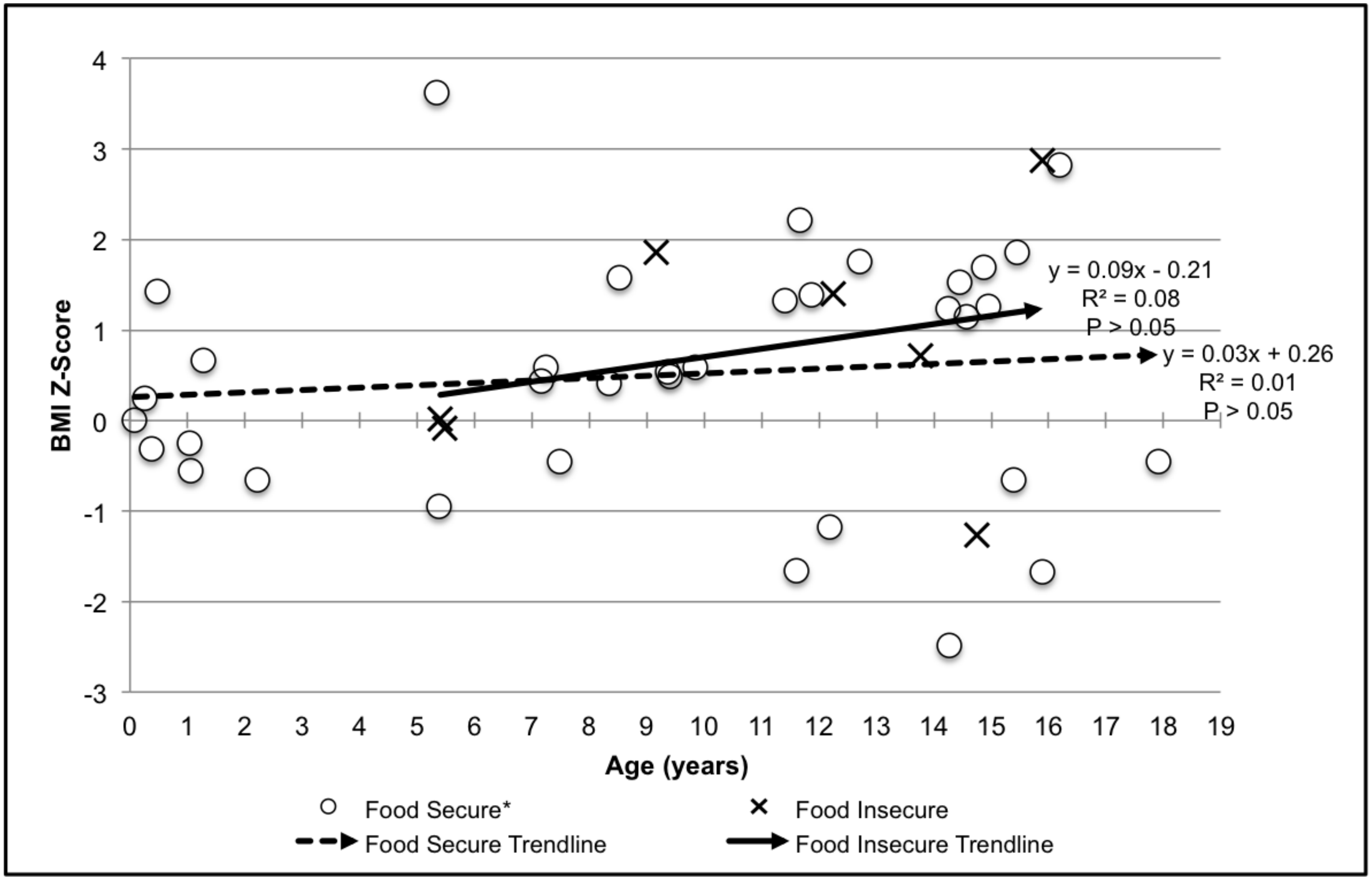
The mean age of children from households that screened food insecure was 11.0 years, which was higher than the mean age of participants who were food secure (9.3 years). A t-test of the difference in mean age between children who were food secure and children who were food insecure shows that the mean ages are not significantly different (See Table 3). When modeled using logistic regression, the relationship between age and food security status was not statistically significant for the sample (OR = 1.1, $P > 0.05$; See Table 4).

Anthropometric Characteristics of Children with and without Food Insecurity

Children from food insecure households had higher weight and height Z-scores than children from food secure households. The mean difference in weight Z-scores between these two groups was -0.6 ($P > 0.05$). The mean difference in height Z-scores was -0.4 ($P > 0.05$). Logistic regression of the relationship between weight and height Z-scores and food security status produced an odds ratio of 1.3 and 1.4, respectively ($P > 0.05$; See Table 4).

The mean BMI Z-score for children from food insecure households (0.8) was higher than the mean BMI Z-score for children who were food secure (0.5). The difference in these means was not statistically significant. A regression model of the relationship between BMI Z-score and food security status produced an odds ratio of 1.2 ($P > 0.05$). The relationship between age and BMI Z-score among children with and without food insecurity is illustrated in Figure 5. Children from food insecure households tended to have higher BMI Z-scores with older age, though the difference in the trendlines between children who were food secure or food insecure was not statistically significant ($P > 0.05$).

Figure 5. Association Between BMI Z-score and Age by Household Food Security Status Among Children with Hemophilia



* The Food Secure data series substitutes weight-for-height Z-scores in place of BMI Z-scores for participants < 2 years of age. The Food Insecure data series uses only BMI Z-scores, as there were no participants <2 years of age

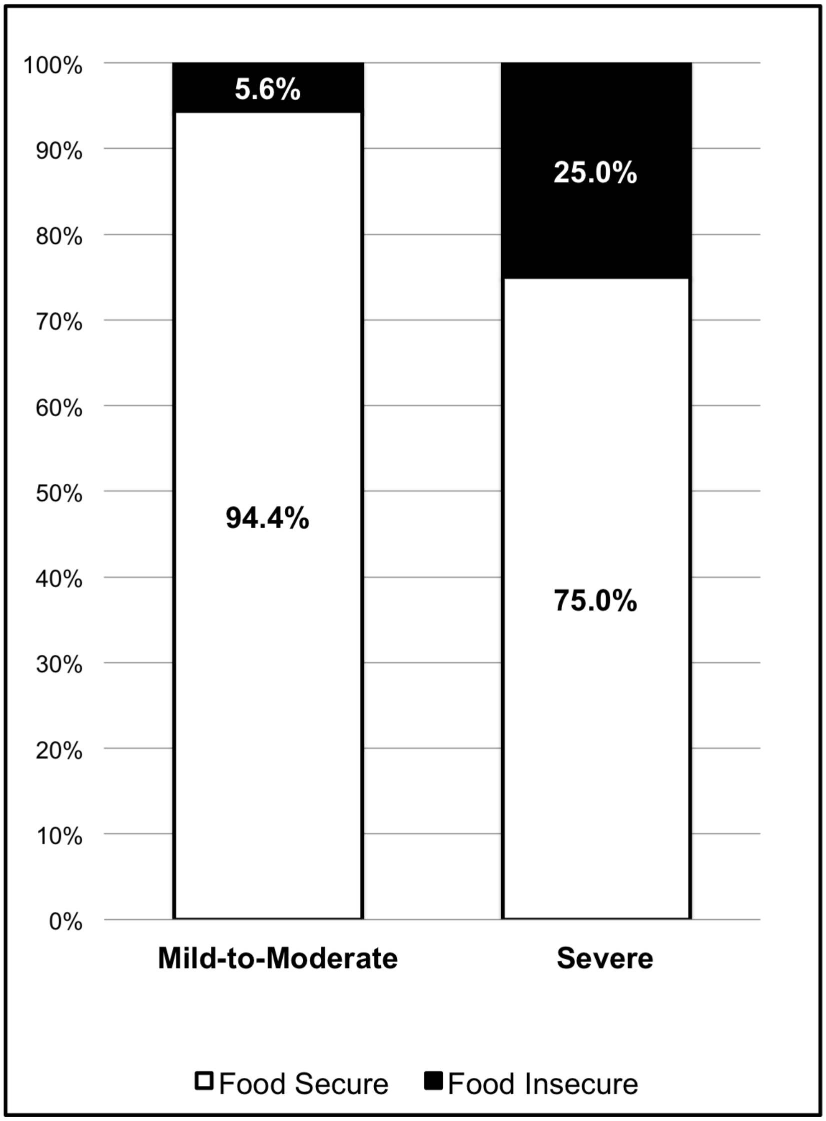
Demographic Characteristics of Children with and without Food Insecurity

The relationship between food security status and race shows a trend toward a statistically significant relationship at P=0.07 for the sample. However, at least one cell had an expected count less than 5. Of the seven participants who were food insecure, two identified as a minority race. A Chi-square test of the relationship between food security status and minority race among participants with severe hemophilia produced a P=0.05. However, at least one cell had an expected count less than 5. Of the six participants with severe hemophilia who were food insecure, two were identified as a minority race. All other Chi-Square tests produced P-values, suggesting no relationship between ethnicity or health insurance type and food security status (See Table 5). Statistical significance of these tests was limited by the small sample and subset size.

Hemophilia-Related Characteristics of Children with and without Food Insecurity

The relationship between food security status and severity of hemophilia or treatment type was not statistically significant. However it is important to note, as shown in Figure 6, the distribution of participants who were food insecure between the subset of those with mild and moderate hemophilia compared to those with severe hemophilia illustrated the concentration of children with food insecurity among those with severe hemophilia.

Figure 6. Household Food Security Status of Children with Mild-to-Moderate or Severe Hemophilia



Other Hemophilia-Related Data

Table 6 shows the normalized factor units per kilogram of body weight per year, ordered factor units per kilogram of body weight per year, and the percent difference between these two measures for the 11 participants who treat their hemophilia prophylactically and order their factor from The Hemophilia Center Factor Program. Significance of these analyses is limited by the small number of participants for whom these data points were available and by the lack of recorded reasons for ordering more or less factor than prescribed.

Table 6. Comparison of Factor Prescribed and Factor Ordered Between Children with and without Food Insecurity

		Food Secure	**Food Insecure**
	n	9	4
Normalized Factor Rx	Mean ± SD	6474 ± 1704	5940 ± 2739
U/Kg BW/Yr[a]	(min, max)	(4763, 9297)	(2419, 8432)
Normalized Factor Ordered	Mean ± SD	6039 ± 1427	4045 ± 2566
U/Kg BW/Yr[a]	(min, max)	(3815, 8352)	(1392, 7314)
% Difference	Mean ± SD	0.95 ± 0.17	0.84 ± 0.45[b]
(Norm Ordered/Norm Rx)	(min, max)	(0.73, 1.26)	(0.20, 1.15)

[a] Units of factor per by kilogram of body weight per year
[b] When outlier is removed, % difference is 1.06 ± 0.16

Chapter V

Discussion

This retrospective, cross-sectional pilot study provided prevalence data and information about predictors of food insecurity otherwise unavailable for children with hemophilia. Using a 2-item validated screening tool, food insecurity was identified as a part of routine clinical care and several characteristics were identified as possible predictors of food insecurity.

The national distribution of cases of hemophilia as 60% severe, 15% moderate, and the remaining 25%, mild.[1-3] This distribution is very similar to the study sample distribution, particularly for the proportion of participants with severe hemophilia. Because of these similarities, it seems valid to generalize results of this study to other populations of children with hemophilia.

Prevalence of Food Insecurity in Households with Children with Hemophilia

The prevalence of household food insecurity for the study sample was 16.7%, which is lower than the current national prevalence for households with children (20.6%[4]), which does not support the study hypothesis. However, the prevalence of household food insecurity among study participants with severe hemophilia was 25.0%, which does support the study hypothesis. The prevalence of household food insecurity for the subset with severe hemophilia is consistent with other studies that estimate the prevalence of household food insecurity for populations of children with other special health care needs, of approximately 25%.[69]

As a pilot study, this information is valuable for practitioners who can take opportunities to incorporate food security screening into routine medical care and target their intervention to those most at risk and those that are identified as food insecure through screening.

Age as a Predictor of Food Insecurity

The mean age of children who were food secure was 9.5 years. However the mean age of children from food insecure households was higher at 11.0 years. These results suggest that children with hemophilia who are older may be more likely to live in a household that experiences food insecurity. There are many circumstances that may contribute to this relationship. As a child gets older they grow and have increased nutritional requirements demanding increased spending on food. Adolescent growth spurts may be a particular challenge for families as nutritional requirements may increase rapidly and drastically. Children over 5 years of age are ineligible for the Supplemental Nutrition Program for Women, Infants and Children (WIC) benefits. Around the time that a child is no longer eligible for WIC benefits, they may become eligible for free or reduced-price meals at school. However, there is a proportion of children who are eligible for school meal programs that do not enroll in the programs. Additionally, as a child with hemophilia grows with age, the amount of factor treatment they need will increase proportionately to their weight. This increase in factor use may put financial strain on the household budget, including food spending.

Anthropometric Predictors of Food Insecurity

Based on the calculated means of anthropometric measurements we can see trends in how growth and development may impact food security status. The weight and height Z-scores of the food insecure subset were higher than the corresponding Z-scores for the food secure subset. The mean BMI Z-score for participants who were food secure was 0.5. The mean BMI Z-score for participants who were food insecure was higher at 0.8.

These findings are consistent previous studies[40,42,47-56] that food insecurity may not have a noticeable adverse effect, or hindrance, on growth. Rather, above average weight or height may put a child at risk for food insecurity because they may require energy and nutrients that their household food budget is insufficient to supply. This finding supports the need for food security status screening independent of observable growth and developmental delays. Experience of food insecurity may be brief and, or recurrent, both situations are unlikely to affect growth, but can still adversely affect other developmental processes. While not statistically significant, the finding that children who were food insecure had a higher mean BMI Z-score than children who were food secure is notable as it is inconsistent with the hypothesis that children who are food insecure may be at risk for increased BMI status due to poor diet quality including consumption of a higher percentage of energy-dense, micronutrient-poor foods.[11,40-46]

As shown in Figure 5, participants who were food insecure tended to have a higher BMI Z-score with older age. The power of this distribution to show a relationship between age and BMI Z-score is limited by the fact that each data point is representative of a different participant and for only one age point. It does not show change in BMI status over time or reflect changes in food security status of a child over time. It only shows a snapshot of BMI status across the sample. With that consideration, it is important to note the higher BMI Z-scores with older age. Among children who were food secure, 10% of BMI status is attributable to age, whereas 30% of BMI status is attributable to age among children who were food insecure. It is particularly important for primary health care providers to assess BMI status among children who are food insecure and offer recommendations to address this trend towards increased BMI status as a child ages.

Demographic Predictors of Food Insecurity

Results of this study suggest a predictive relationship between race and ethnicity and food insecurity. The prevalence of food insecurity among participants identified as a minority race or ethnicity was high (44.4%, n=9). Four of the seven participants who were food insecure were identified as a minority race or ethnicity. These findings are consistent with the study hypothesis and current literature describing higher prevalence of household food insecurity in households identified as a minority race or ethnicity, particularly Black and Hispanic families.[4]

A relationship between insurance type and food security status could not be confirmed. However the proportion of participants with public health care insurance who were food insecure (29.4%) is one of the highest among all subsets. This is likely attributable to a lower household income and concurrent food insecurity, potentiating a participant's eligibility for Medicaid health coverage. Further study including household income will be helpful in investigating this relationship.

Hemophilia-Related Predictors of Food Insecurity

The results of this study suggest that severity of hemophilia is not related to food security status. However as a pilot study with a small sample size, it is important to note that of the 7 participants who were food insecure, 6 had severe hemophilia. A larger sample size may have helped the relationship between severity of hemophilia and food security status reach statistical significance. Figure 6 shows the concentration of children who were food insecure within the severe hemophilia category. If 20.6% of US households with children are food insecure, and 25.0% of households including a child with severe hemophilia are food insecure, then children with severe hemophilia are at over 21% increased risk for food insecurity. Future studies of larger sample size should be conducted to confirm this relationship. This finding is consistent with the study hypothesis.

Analyses of the relationship between type of hemophilia treatment and food security status suggest no statistically significant relationship. These results are similar to those of severity of hemophilia and food security status because most of the participants who had severe hemophilia were on a prophylaxis treatment regimen. As a pilot study, it is important to note that of the 7 participants who were food insecure, 6 used prophylactic treatment to manage their hemophilia.

Limitations

The findings of this study were limited by the small sample size and cross-sectional collection of data. Power analyses suggest limited power to identify statistically significant results. For example, the power to test if the overall prevalence of food insecurity (16.7%) was different from the 2011 US national average (20.6%) was 13.4%. If you consider only the children with severe hemophilia (food insecure = 25.0%) compared to the national average, the power is only 15.0%. The power to test the difference in proportions of food secure and food insecure households between mild-to-moderate (food insecure = 5.6%) or severe (food insecure = 25.0%) hemophilia categories was 51.1%. Study variables and analyses were limited to the data collected as part of routine clinical care and available in medical records. Additional data on factor use and food aid resources used may have provided more perspective on how food insecurity affects children with hemophilia and how families cope with food insecurity.

Contributions

In spite of these limitations, this study provides data on food insecurity in children with hemophilia otherwise unpublished and adds to the small body of literature describing food insecurity in populations of children with special health care needs.

Future Directions

Future efforts of food security research need to build the body of evidence to clearly demonstrate the prevalence of food insecurity and associated consequences in populations that may be at increased risk. The feasibility of screening for household food insecurity and intervening to improve outcomes needs to be clearly documented. This is the only way that screening will become a routine practice and an established component of medical records in all clinics and health care environments that may have the opportunity to identify and reduce the presence of food insecurity among children and their families.

As food security screening becomes a more common practice, it could be valuable to study trends in household food security related to time of screening during the year or month. There are many factors that could impact household food security during the year. The costs of heating or cooling a home are highest during the winter and summer, respectively, and may place financial burden on a household. At the beginning of the year a family may have to begin paying a health insurance deductible again. Summer break from school may require families to pay for daycare programs or transportation to summer meal sites may be difficult if parents are working.

Even though food security screening tools ask participants to consider their experiences over the previous twelve months, there may be an unintentional bias in the results depending on what time of the month a household is screened. If the family is running out of SNAP benefits at the end of the month, they may perceive their situation differently than if they had just received benefits. These are just a few problems that may be addressed by future food security research.

Conclusions

This study provides a foundational understanding of how hemophilia can increase risk of food insecurity among children and their families, particularly for children with severe hemophilia. Food insecurity is a problem among children with hemophilia and screening and intervention need to be an integral part of routine clinical care.

While the sample size and availability of data points were limited, it is clear that a 2-item screener can be used efficiently and successfully to identify households that experience food insecurity and who could benefit from intervention including information about and access to food aid and other financial resources. As outlined the Childhood Hunger Coalition Screening and Intervention Algorithm (See Appendix B), interventions for food insecurity may include extensive growth, development, and nutrition assessment performed by the screening health care provider, or referral to other health care professionals including registered dietitians and social workers.

Organizations like the Childhood Hunger Coalition and institutions like Oregon Health & Science University have created and are continuing to develop resources to assist health care providers in screening and intervening to reduce the number of children and families that needlessly struggle to have enough nutritionally adequate and safe foods.

References

1. Butler RB, Crudder SO, Riske B, Toal S. Basic Concepts of Hemophilia. 2nd ed. Centers for Disease Control and Prevention: Department of Health & Human Services U.S.A, 2007.

2. Brown R, Cornett J. The Hemophilia Handbook. 3rd ed. Hemophilia of Georgia, Inc, 1998.

3. National Hemophilia Foundation. Version current 2006. Internet: www.hemophilia.org (accessed January 2012).

4. Coleman-Jensen A, Nord M, Andrews M, Carlson S. Household food security in the United States in 2011. Econ. Res. Serv.: U.S. Dept. of Agriculture, 2012. no. ERR-141.

5. Cook JT, Frank DA, Levenson SM, et al. Child food insecurity increases risks posed by household food insecurity to young children's health. J Nutr 2006;136:1073-6.

6. Jyoti DF, Frongillo EA, Jones SJ. Food insecurity affects school children's academic performance, weight gain, and social skills. J Nutr 2005;135:2831-9.

7. Cook JT, Frank DA, Berkowitz C, et al. Food insecurity is associated with adverse health outcomes among human infants and toddlers. J Nutr 2004;134:1432-8.

8. Weinreb L, Wehler C, Perloff J, et al. Hunger: its impact on children's health and mental health. Pediatrics 2002;110:e41.

9. Alaimo K, Olson CM, Frongillo EA,Jr. Food insufficiency and American school-aged children's cognitive, academic, and psychosocial development. Pediatrics 2001;108:44-53.

10. Alaimo K, Olson CM, Frongillo EA,Jr, Briefel RR. Food insufficiency, family income, and health in US preschool and school-aged children. Am J Public Health 2001;91:781-6.

11. Casey PH, Szeto K, Lensing S, Bogle M, Weber J. Children in food-insufficient, low-income families: prevalence, health, and nutrition status. Arch Pediatr Adolesc Med 2001;155:508-14.

12. Kleinman RE, Murphy JM, Little M, et al. Hunger in children in the United States: potential behavioral and emotional correlates. Pediatrics 1998;101:E3.

13. Hoisington AT, Braverman MT, Hargunani DE, Adams EJ, Alto CL. Health care providers' attention to food insecurity in households with children. Prev Med 2012;55:219-22.

14. Bickel G, Nord M, Price C, Hamilton W, Cook J. Guide to measuring household food security, Revised 2000. U.S. Dept. of Agriculture, 2000. no. Food and Nut. Serv.]

15. Cook JT, Jeng K. Childhood food insecurity: The economic impact on our nation. Feeding America, 2009.

16. Anonymous Healthy People 2020. Version current November 2011. Internet: http://www.healthypeople.gov/2020/default.aspx (accessed December 2011).

17. Whitaker RC, Phillips SM, Orzol SM. Food insecurity and the risks of depression and anxiety in mothers and behavior problems in their preschool-aged children. Pediatrics 2006;118:e859-68.

18. Alaimo K, Briefel RR, Frongillo EA,Jr, Olson CM. Food insufficiency exists in the United States: results from the third National Health and Nutrition Examination Survey (NHANES III). Am J Public Health 1998;88:419-26.

19. Hager ER, Quigg AM, Black MM, et al. Development and validity of a 2-item screen to identify families at risk for food insecurity. Pediatrics 2010;126:e26-32.

20. Hill BG, Moloney AG, Mize T, Himelick T, Guest JL. Prevalence and predictors of food insecurity in migrant farmworkers in Georgia. Am J Public Health 2011;101:831-3.

21. Wehler C, Weinreb LF, Huntington N, et al. Risk and protective factors for adult and child hunger among low-income housed and homeless female-headed families. Am J Public Health 2004;94:109-15.

22. Bartfeld J, Dunifon R. State-level predictors of food insecurity and hunger among households with children. www.ers.usda.gov: U.S. Dept. of Agriculture, 2005. no. ERR-13.

23. Cutts DB, Meyers AF, Black MM, et al. US Housing insecurity and the health of very young children. Am J Public Health 2011;101:1508-14.

24. Kirkpatrick SI, Tarasuk V. Housing circumstances are associated with household food access among low-income urban families. J Urban Health 2011;88:284-96.

25. Ma CT, Gee L, Kushel MB. Associations between housing instability and food insecurity with health care access in low-income children. Ambul Pediatr 2008;8:50-7.

26. Frank DA, Neault NB, Skalicky A, et al. Heat or eat: the Low Income Home Energy Assistance Program and nutritional and health risks among children less than 3 years of age. Pediatrics 2006;118:e1293-302.

27. Kushel MB, Gupta R, Gee L, Haas JS. Housing instability and food insecurity as barriers to health care among low-income Americans. J Gen Intern Med 2006;21:71-7.

28. Meyers A, Frank DA, Roos N, et al. Housing subsidies and pediatric undernutrition. Arch Pediatr Adolesc Med 1995;149:1079-84.

29. Meyers A, Rubin D, Napoleone M, Nichols K. Public housing subsidies may improve poor children's nutrition. Am J Public Health 1993;83:115.

30. Skalicky A, Meyers AF, Adams WG, Yang Z, Cook JT, Frank DA. Child food insecurity and iron deficiency anemia in low-income infants and toddlers in the United States. Matern Child Health J 2006;10:177-85.

31. Kirkpatrick SI, McIntyre L, Potestio ML. Child hunger and long-term adverse consequences for health. Arch Pediatr Adolesc Med 2010;164:754-62.

32. Seligman HK, Laraia BA, Kushel MB. Food insecurity is associated with chronic disease among low-income NHANES participants. J Nutr 2010;140:304-10.

33. Miller E, Wieneke KM, Murphy JM, et al. Child and parental poor health among families at risk for hunger attending a community health center. J Health Care Poor Underserved 2008;19:550-61.

34. Bierman AS, Dunn JR. Swimming upstream. Access, health outcomes, and the social determinants of health. J Gen Intern Med 2006;21:99-100.

35. Casey PH, Szeto KL, Robbins JM, et al. Child health-related quality of life and household food security. Arch Pediatr Adolesc Med 2005;159:51-6.

36. Trzepacz AM, Vannatta K, Davies WH, Stehbens JA, Noll RB. Social, emotional, and behavioral functioning of children with hemophilia. J Dev Behav Pediatr 2003;24:225-32.

37. Murphy JM, Wehler CA, Pagano ME, Little M, Kleinman RE, Jellinek MS. Relationship between hunger and psychosocial functioning in low-income American children. J Am Acad Child Adolesc Psychiatry 1998;37:163-70.

38. Melchior M, Caspi A, Howard LM, et al. Mental health context of food insecurity: a representative cohort of families with young children. Pediatrics 2009;124:e564-72.

39. Frongillo EA, Jyoti DF, Jones SJ. Food Stamp Program participation is associated with better academic learning among school children. J Nutr 2006;136:1077-80.

40. Eisenmann J, Alaimo K, Pfeiffer K, et al. Project FIT: rationale, design and baseline characteristics of a school- and community-based intervention to address physical activity and healthy eating among low-income elementary school children. Advance data JID - 7703830 2011.

41. Kirkpatrick SI, Tarasuk V. Food insecurity is associated with nutrient inadequacies among Canadian adults and adolescents. J Nutr 2008;138:604-12.

42. Dinour LM, Bergen D, Yeh MC. The food insecurity-obesity paradox: a review of the literature and the role food stamps may play. J Am Diet Assoc 2007;107:1952-61.

43. Rose D. Economic determinants and dietary consequences of food insecurity in the United States. J Nutr 1999;129:517S-20S.

44. Rose D, Habicht JP, Devaney B. Household participation in the Food Stamp and WIC programs increases the nutrient intakes of preschool children. J Nutr 1998;128:548-55.

45. Rose D, Oliveira V. Nutrient intakes of individuals from food-insufficient households in the United States. Am J Public Health 1997;87:1956-61.

46. Emmons L. Relationship of participation in food assistance programs to the nutritional quality of diets. Am J Public Health 1987;77:856-8.

47. Eisenmann JC, Gundersen C, Lohman BJ, Garasky S, Stewart SD. Is food insecurity related to overweight and obesity in children and adolescents? A summary of studies, 1995-2009. Obes Rev 2011;12:e73-83.

48. Larson NI, Story MT. Food insecurity and weight status among U.S. children and families: a review of the literature. Am J Prev Med 2011;40:166-73.

49. Garasky S, Stewart SD, Gundersen C, Lohman BJ, Eisenmann JC. Family stressors and child obesity. Soc Sci Res 2009;38:755-66.

50. Gundersen C, Garasky S, Lohman BJ. Food insecurity is not associated with childhood obesity as assessed using multiple measures of obesity. J Nutr 2009;139:1173-8.

51. Lohman BJ, Stewart S, Gundersen C, Garasky S, Eisenmann JC. Adolescent overweight and obesity: links to food insecurity and individual, maternal, and family stressors. J Adolesc Health 2009;45:230-7.

52. Gundersen C, Lohman BJ, Garasky S, Stewart S, Eisenmann J. Food security, maternal stressors, and overweight among low-income US children: results from the National Health and Nutrition Examination Survey (1999-2002). Pediatrics 2008;122:e529-40.

53. Casey PH, Simpson PM, Gossett JM, et al. The association of child and household food insecurity with childhood overweight status. Pediatrics 2006;118:e1406-13.

54. Dubois L, Farmer A, Girard M, Porcherie M. Family food insufficiency is related to overweight among preschoolers. Soc Sci Med 2006;63:1503-16.

55. Rose D, Bodor JN. Household food insecurity and overweight status in young school children: results from the Early Childhood Longitudinal Study. Pediatrics 2006;117:464-73.

56. Alaimo K, Olson CM, Frongillo EA,Jr. Low family income and food insufficiency in relation to overweight in US children: is there a paradox? Arch Pediatr Adolesc Med 2001;155:1161-7.

57. Cook JT, Frank DA, Casey PH, et al. A brief indicator of household energy security: associations with food security, child health, and child development in US infants and toddlers. Pediatrics 2008;122:e867-75.

58. Alaimo K, Olson CM, Frongillo EA. Family food insufficiency, but not low family income, is positively associated with dysthymia and suicide symptoms in adolescents. J Nutr 2002;132:719-25.

59. Ramsey R, Giskes K, Turrell G, Gallegos D. Food insecurity among Australian children: potential determinants, health and developmental consequences. J Child Health Care 2011;15:401-16.

60. Kleinman RE, Hall S, Green H, et al. Diet, breakfast, and academic performance in children. Ann Nutr Metab 2002;46 Suppl 1:24-30.

61. Cook JT. Clinical implications of household food security: definitions, monitoring, and policy. Nutr Clin Care 2002;5:152-67.

62. Gundersen C, Lohman BJ, Eisenmann JC, Garasky S, Stewart SD. Child-specific food insecurity and overweight are not associated in a sample of 10- to 15-year-old low-income youth. J Nutr 2008;138:371-8.

63. Screening for Risk in the Clinical Setting. Internet: www.childhoodhunger.com Childhood Hunger Coalition, 2008. (accessed September 2012)

64. Childhood hunger: A public health concern. Screening and intervention in the clinic. www.childhoodhunger.com. Childhood Hunger Coalition, 2010. (accessed September 2012)

65. Nord M. How much does the Supplemental Nutrition Assistance Program alleviate food insecurity? Evidence from recent programme leavers. Public Health Nutr 2011;1-7.

66. Kleinman RE, Murphy JM, Wieneke KM, Desmond MS, Schiff A, Gapinski JA. Use of a single-question screening tool to detect hunger in families attending a neighborhood health center. Ambul Pediatr 2007;7:278-84.

67. Ljung R, van den Berg M, Valentino LA, Manco-Johnson M. The Fourth Annual Meeting of the International Network for Pediatric Hemophilia: Current Challenges and Recommendations in the Clinical Care of Children with Hemophilia. Transfus Med Hemother 2010;37:209-12.

68. Mercan A, Sarper N, Inanir M, et al. Hemophilia-Specific Quality of Life Index (Haemo-QoL and Haem-A-QoL questionnaires) of children and adults: result of a single center from Turkey. Pediatr Hematol Oncol 2010;27:449-61.

69. Childhood Hunger Initiative of Oregon. Childhood Food Insecurity: Health Impacts, Screening, and Intervention. Online Course. http://ecampus.oregonstate.edu/workforce/childhood-food-insecurity/. Accessed 6/9/2012.

Appendix A

USDA Core Food Security Module: Household Food Security Survey[4]

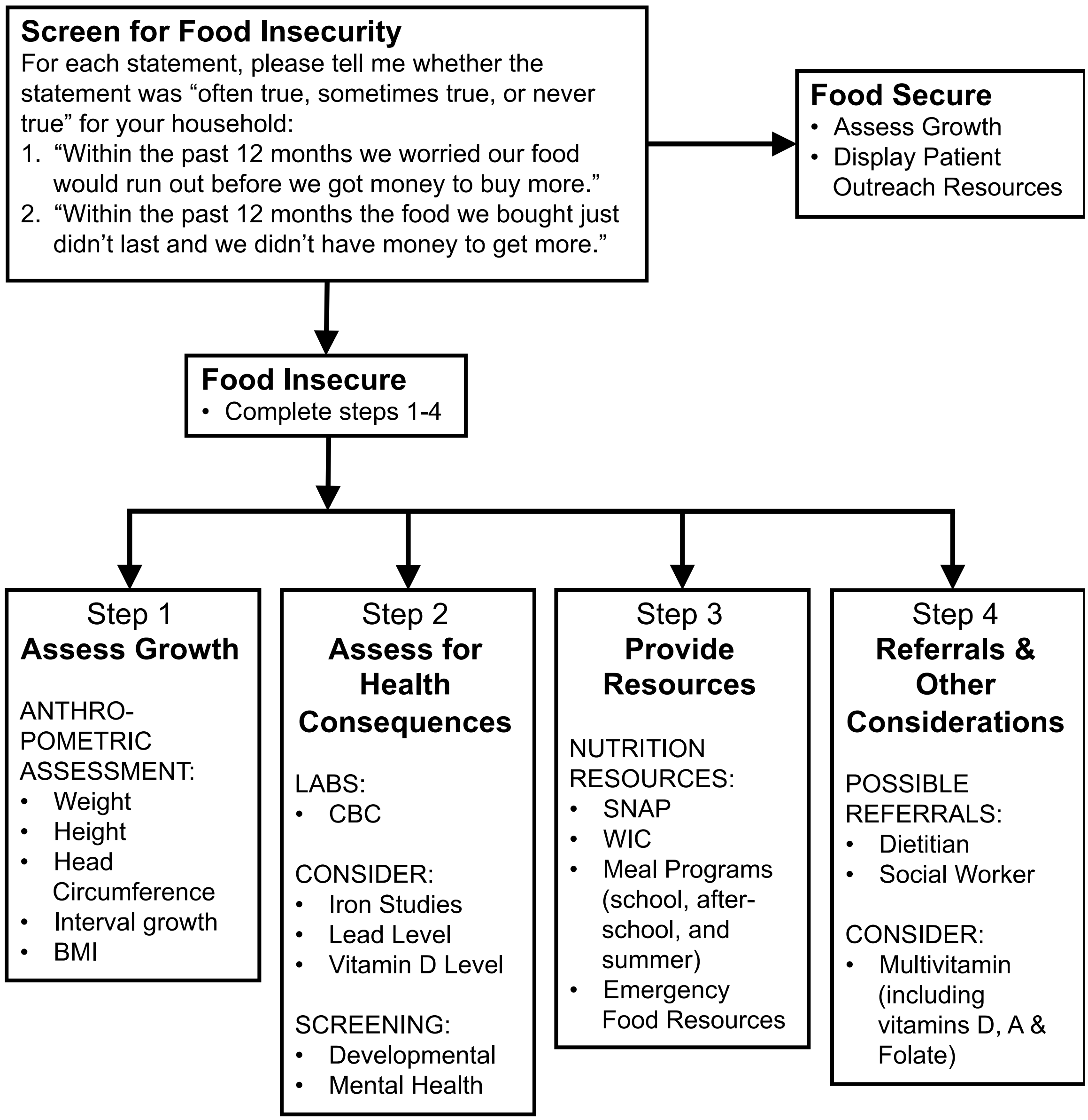
1. “We worried whether our food would run out before we got money to buy more.” Was that often, sometimes, or never true for you in the last 12 months?
2. “The food that we bought just didn’t last and we didn’t have money to get more.” Was that often, sometimes, or never true for you in the last 12 months?
3. “We couldn’t afford to eat balanced meals.” Was that often, sometimes, or never true for you in the last 12 months?
4. In the last 12 months, did you or other adults in the household ever cut the size of you meals or skip meals because there wasn’t enough money for food? (Yes/No)
5. (If yes to question 4) How often did this happen—almost every month, some months but not every month, or in only 1 or 2 months?
6. In the last 12 months, did you ever eat less than you felt you should because there wasn’t enough money for food? (Yes/No)
7. In the last 12 months, were you ever hungry, but didn’t eat, because there wasn’t enough money for food? (Yes/No)
8. In the last 12 months, did you lose weight because there wasn’t enough money for food? (Yes/No)
9. In the last 12 months, did you or other adults in your household ever not eat for a whole day because there wasn’t enough money for food? (Yes/No)
10. (If yes to question 9) How often did this happen—almost every month, some months but not every month, or in only 1 or 2 months?

(Questions 11-18 are asked only if the household includes children age 0-17)

11. “We relied on only a few kinds of low-cost food to feed our children because we were running out of money to buy food.” Was that often, sometimes, or never true for you in the last 12 months?
12. “We couldn’t feed our children a balanced meal, because we couldn’t afford that.” Was that often, sometimes, or never true for you in the last 12 months?
13. “The children were not eating enough because we just couldn’t afford enough food.” Was that often, sometimes, or never true for you in the last 12 months?
14. In the last 12 months, did you ever cut the size of any of the children’s meals because there wasn’t enough money for food? (Yes/No)
15. In the last 12 months, were the children ever hungry, but you just couldn’t afford more food? (Yes/No)
16. In the last 12 months, did any of the children ever skip a meal because there wasn’t enough money for food? (Yes/No)
17. (If yes to question 16) How often did this happen—almost every month, some months but not every month, or in only 1 or 2 months?
18. In the last 12 months, did any of the children ever not eat for a whole day because there wasn’t enough money for food? (Yes/No)

Appendix B

Childhood Hunger Coalition Screening & Intervention Algorithm



Appendix C

REDCap Data Collection Form

Study ID	
DEMOGRAPHIC DATA	
Date of Screening*	
MRN*	
Name*	
Eligible for Inclusion?	☐ Yes ☐ No (younger sibling included)
Date of Birth*	
Age at Screening (years)	
Gender	☐ Male ☐ Female
Language Spoken	☐ English ☐ Spanish ☐ Other
Race	☐ White ☐ Black ☐ American Indian, Alaskan Native ☐ Asian ☐ Native Hawaiian, Pacific Islander ☐ Other
Ethnicity	☐ Not Hispanic or Latino ☐ Hispanic or Latino
Insurance Type	☐ Private ☐ Public ☐ None
ANTHROPOMETRIC DATA	
Weight (kg)	
Weight-for-Age Z-score	
Height/Length (cm)	
Height/Length Z-score	
BMI	
BMI Z-score	
Weight-for-Length (%ile)	
Weight-for-Length (%ile) Z-score	

*Data point marked as an identifier and not exported from REDCap.

Appendix C continued next page…

Appendix C continued:

HEMOPHILIA DATA	
Hemophilia Type	☐ A ☐ B
Severity of Hemophilia	☐ Mild ☐ Moderate ☐ Severe
Bleeding Episodes (# in past year)	
Factor Treatment	☐ None ☐ On Demand ☐ Prophylaxis
Factor Rx Dosage (units)	
Factor Rx Infusion Frequency (# per week)	
Normalized Factor Infusion (units/kg BW/yr)	
Factor Units Ordered (units/year)	
FOOD SECURITY STATUS DATA	
Screener Question 1	☐ Often ☐ Sometimes ☐ Never
Screener Question 2	☐ Often ☐ Sometimes ☐ Never
Food Security Status	☐ Food Secure ☐ Food Insecure
Food Aid Resources	☐ SNAP ☐ TANF ☐ WIC ☐ School Breakfast ☐ School Lunch ☐ School Summer Meals ☐ Food Bank ☐ Congregate Meals ☐ Emergency Food Package ☐ Other ____________________

TABLE OF CONTENTS

List of Abbreviations and Acronyms

BMI	Body Mass Index
CDC	Centers for Disease Control and Prevention
CHC	Childhood Hunger Coalition
CPS	Current Population Survey
HFSS	Household Food Security Survey
NHANES	National Health and Nutrition Examination Survey
NSBP	National School Breakfast Program
OHSU	Oregon Health & Science University
SFSP	School Food Service Program
SLP	School Lunch Program
SNAP	Supplemental Nutrition Assistance Program
TANF	Temporary Aid for Needy Families
US	United States
USDA	United States Department of Agriculture
WIC	Supplemental Nutrition Program for Women, Infants, and Children

List of Figures

List of Tables

Acknowledgements

First I would like to thank my mentor, Dr. Elizabeth Adams, for offering to bring me on to this research project. I have appreciated your guidance and support and I am grateful to have had the opportunity to study something as globally relevant as food insecurity. This thesis has forever changed my perspective of my own nutrition practice to necessarily include food security screening and intervention.

To my committee members, Dr. Diane Stadler and Dr. Michael Recht, thank you very much for all of your time and effort to provide guidance, support, and endless suggestions for revision. My work is certainly more thorough and polished because of your keen eyes and constant inspiration to push my thinking and subsequent writing beyond what I am capable of on my own. A special thanks goes to Michael Lasarev (Research Associate, CROET), for statistical consultation.

To The Hemophilia Center at Oregon Health & Science University, thank you for caring immensely for your patients and for recognizing the importance of food security screening and intervention. Your work is already encouraging other health care providers to follow your example and so many other children may one day suffer less from food insecurity because of your initiative.

And finally, to my husband, Ryan; my parents, Joe and Kathy; and my closest friends—your unwavering love, support, and encouragement have seen me through every moment and effort of this project. I could not have accomplished this incredible goal without you.

Abstract

Background: Food insecurity, the limited or uncertain availability of nutritionally adequate and safe food, negatively affects children's development and health. Households including children with hemophilia may be at increased risk for food insecurity due to hemophilia-related medical expenses.

Objectives: The purpose of this pilot study was to determine the prevalence and predictors of food insecurity among children with hemophilia and their families.

Methods: Data on household food insecurity and health status, as assessed at annual comprehensive clinical appointments of children with hemophilia between May 2012-January 2013, were obtained by chart review. Descriptive statistics were applied to summarize participant characteristics. Chi-Square analyses, t-testing, and logistic regression models were used to demonstrate associations between food security status and participant characteristics.

Results: Data were available for 42 male participants, aged 0-17 years. By severity, 42.9% had mild or moderate hemophilia, and 57.1% severe. Sample prevalence of household food insecurity was 16.7% (95% CI, 5.4-28.0%), lower than the national prevalence among all households with children. Food insecurity was rare among households with children with mild and moderate disease (5.6%; 95% CI, 0-16.2%) and concentrated among households with children with severe disease (25.0%; 95% CI, 7.7-42.3%). Households with children who were older, taller, heavier, had higher BMI, or were a minority race or ethnicity were at increased risk for food insecurity (all $P>0.05$).

Conclusions: Households with children with severe hemophilia are at increased risk for food insecurity. This study provides pilot data showing the need for screening and linkage to resources as a routine part of care, and demonstrates a need for improved understanding of the predictors of food insecurity in households with children with hemophilia.

School of Medicine

Oregon Health & Science University

CERTIFICATE OF APPROVAL

This is to certify I have read the Master's thesis of

Sarah Kathryn Ziha

And approve the research outlined herein

Diane Stadler, PhD, RD, LD

Elizabeth Adams, PhD, RD, LD

Michael Recht, PhD, MD