2012

The Massachusetts Bmi Letter: Parents' Responses, Conceptualizations of Weight, and Health Literacy Skills

Lindsay J. Moyer

University of Massachusetts Amherst

Follow this and additional works at: https://scholarworks.umass.edu/theses


This thesis is brought to you for free and open access by ScholarWorks@UMass Amherst. It has been accepted for inclusion in Masters Theses 1911 - February 2014 by an authorized administrator of ScholarWorks@UMass Amherst. For more information, please contact scholarworks@library.umass.edu.
THE MASSACHUSETTS BMI LETTER: PARENTS’ RESPONSES, CONCEPTUALIZATIONS OF WEIGHT, AND HEALTH LITERACY SKILLS

A Thesis Presented

by

LINDSAY MOYER

Approved as to style and content by:

__________________________________________
Elena T. Carbone, Chair

__________________________________________
Jean A. Anliker, Member

__________________________________________
Jerusha N. Peterman, Member

Nancy L. Cohen, Department Head
Department of Nutrition
ACKNOWLEDGMENTS

I would like to thank my advisor and chair, Dr. Elena Carbone, for dedicating her time and allowing me to participate in her research project to make this thesis possible. Dr. Carbone has been an excellent, patient editor, and has taught me a great deal about the research and writing process. Her clear enthusiasm for her work has inspired me as I begin my career in nutrition.

I would also like to thank my committee members, Dr. Jean Anliker and Dr. Jerusha Peterman. Dr. Anliker’s input into the design and implementation of this project was essential, and her positive attitude was contagious. Dr. Peterman provided kind words and valued guidance throughout the project, including my training in the qualitative software.

Special thanks to Dr. Sarah Goff for making this research possible and for providing thoughtful feedback throughout the process. In addition, I would like to acknowledge Brenda Peters for her much needed help in recruitment and data collection. Thanks to Hilary Weiner and Kara Swain of the MIGHTY program. Their assistance and flexibility throughout the study allowed recruitment and focus groups to proceed smoothly.

I would also like to thank my classmates, friends, and family for their invaluable support throughout my time in graduate school.
ABSTRACT

THE MASSACHUSETTS BMI LETTER: PARENTS’ RESPONSES, CONCEPTUALIZATIONS OF WEIGHT, AND HEALTH LITERACY SKILLS

SEPTEMBER 2012

LINDSAY MOYER, B.A., LEHIGH UNIVERSITY

M.S., UNIVERSITY OF MASSACHUSETTS AMHERST

Directed by: Professor Elena Carbone

BACKGROUND: Since 2010, nurses in Massachusetts public schools have conducted state-mandated Body Mass Index (BMI) screening of first, fourth, seventh, and tenth graders and communicated results in a letter to parents/caregivers. The objective of this study was to explore parents’ responses to the BMI letter and their experiences with weight-related language used by health professionals. These two areas were examined in the context of parents’ health literacy skills and readability of the letter. METHODS: Readability of the letter was calculated using five common formulas. One-hour focus groups were conducted using a semi-structured interview guide with a convenience sample of parents/caregivers of 8- to 14-year-old obese children participating in a weight management program. Parents were asked to share reactions to 10 weight terms in random order. Parents also completed a written version of the Newest Vital Sign (NVS) health literacy assessment. Focus group data were transcribed verbatim, and content analyses conducted to identify emergent themes. Descriptive statistics were calculated for NVS scores. RESULTS: Reading-level
estimates of the BMI letter ranged from fifth to seventh grade. Twenty-nine individuals participated in eight focus groups (83% female, mean age 41 yrs±9 yrs, 59% self-identified as Hispanic/Latino). NVS scores for 12 participants (41%) indicated a possibility (n=7) or high likelihood (n=5) of limited health literacy. “Emotions” emerged as a major theme. Parents expressed concern, guilt, fear, anger, rationalization, skepticism, and acceptance regarding the letter and weight-related terms. Parents had mixed reactions to the letter: finding the information helpful, voicing concern about privacy and self-esteem, and displaying confusion when interpreting the weight status. A majority (67%) of parents who expressed confusion about the letter or weight terminology received an NVS score indicating a possibility or high likelihood of limited health literacy. Among the weight terms, parents preferred weight, weight problem, and unhealthy weight more than obese or extremely obese. CONCLUSIONS: This is the first known study to evaluate how parents respond to and comprehend the Massachusetts BMI letter. Emergent themes could be used to inform quantitative assessment of communication challenges associated with the letter. This study has implications for respectfully and effectively communicating BMI results nationwide.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACKNOWLEDGMENTS</td>
<td>iv</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td>iv</td>
</tr>
<tr>
<td>LIST OF TABLES</td>
<td>xii</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
<td>xiii</td>
</tr>
<tr>
<td><strong>CHAPTER</strong></td>
<td></td>
</tr>
<tr>
<td>1. INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>2. PERCEPTION OF CHILDREN’S WEIGHT</td>
<td>4</td>
</tr>
<tr>
<td>Parents’ Perception of Children’s Weight</td>
<td>4</td>
</tr>
<tr>
<td>Parents’ Perception of Children’s Weight-Related Health</td>
<td>6</td>
</tr>
<tr>
<td>Factors Associated with Parents’ Perception of Children’s Weight</td>
<td>9</td>
</tr>
<tr>
<td>Parent and Family Characteristics</td>
<td>9</td>
</tr>
<tr>
<td>Culture/Ethnicity</td>
<td>9</td>
</tr>
<tr>
<td>Parents’ BMI</td>
<td>11</td>
</tr>
<tr>
<td>Parents’ Education</td>
<td>12</td>
</tr>
<tr>
<td>Parents’ Numeracy</td>
<td>13</td>
</tr>
<tr>
<td>Child Characteristics</td>
<td>15</td>
</tr>
<tr>
<td>Child’s Age</td>
<td>15</td>
</tr>
<tr>
<td>Child’s Gender</td>
<td>17</td>
</tr>
<tr>
<td>Child’s BMI</td>
<td>17</td>
</tr>
<tr>
<td>Societal Factors</td>
<td>18</td>
</tr>
<tr>
<td>Changing Weight-Related Norms</td>
<td>18</td>
</tr>
<tr>
<td>Limitations and Future Research Needs</td>
<td>18</td>
</tr>
<tr>
<td>3. COMMUNICATION AND CONCEPTUALIZATION OF WEIGHT</td>
<td>22</td>
</tr>
<tr>
<td>Communication and Conceptualization of Adults’ Weight</td>
<td>22</td>
</tr>
</tbody>
</table>
Frequency of Weight Communication with Physicians ............... 22
Patient Preferences for Specific Weight-Related Language .......... 24

Communication and Conceptualization of Children's Weight ........ 31

Preschool-Age Children ............................................. 32
Older Children and Adolescents .................................... 33
Hurtful Communication ............................................... 36
Approaches to Communication in Clinical Settings ................ 37

Summary of Findings .................................................................. 38

4. COMMUNICATING CHILDREN’S WEIGHT WITH THE BMI LETTER .... 39

Communicating with Parents about BMI in Schools .................... 41
Student Perspectives on BMI Communication in Schools ............... 44
Experimental Research on BMI Communication in Schools .......... 45
Need for Qualitative Research on BMI Communication in Schools ... 46
Summary of Findings and Research Needs .............................. 47
Need for Investigation of Health Literacy ................................ 49

5. HEALTH LITERACY .................................................................. 51

Definition of Health Literacy ..................................................... 51
Prevalence of Limited Literacy and Limited Health Literacy .......... 54
History of Health Literacy as a Field of Study ......................... 56
Factors Associated with Limited Health Literacy ....................... 57
Measurement of Health Literacy .............................................. 58

Limitations of Healthy Literacy Measurements ................................ 63

Measurement of Readability ................................................. 66
Health Literacy and Nutrition ................................................. 67

Health Literacy and Chronic Disease Management ..................... 67
Health Literacy and Diabetes Outcomes .................................... 68
Factors Connecting Low Health Literacy and Diabetes Outcomes .................................................. 68
Poor Readability of Traditional Diabetes Diet Education Materials ............................................. 70
Efficacy of Literacy- and Numeracy-Adapted Education Materials .................................................. 72
Health Literacy, Weight Management, and Dietary Behaviors .... 75
Future Research Needs in Nutrition and Health Literacy .......... 75

Future Research Needs in Health Literacy and BMI Screening ...... 81
Demographics........................................................................................................... 122
Readability ................................................................................................................ 122
Health Literacy ......................................................................................................... 126

Newest Vital Sign Scores......................................................................................... 126
Feasibility of the Newest Vital Sign in a Group Setting ........................................ 128

Focus Groups ........................................................................................................... 129

Overall Theme of “Emotions” ................................................................................. 129
Weight Communication ......................................................................................... 131
Response to the BMI Letter ................................................................................. 134

Reactions to the BMI Letter .................................................................................. 134
Confusion about the BMI Letter ........................................................................... 136

Strengths and Limitations ...................................................................................... 138

Strengths of the Study ........................................................................................... 138
Limitations of the Study ......................................................................................... 139

Implications for Research and Practice ............................................................... 141

Implications for Public Health and Clinical Practice ........................................... 142

Use of Readability Formulas ................................................................................ 142
Measurement of Health Literacy ........................................................................... 143
Patient-Provider Communication ......................................................................... 143
Recommendations for the BMI Letter ................................................................ 144

Implications and for Future Research ................................................................. 146

11. CONCLUSIONS .................................................................................................. 149

APPENDICES

A. RECRUITMENT FLYER ......................................................................................... 168
B. RECRUITMENT DAY OUTLINE ......................................................................... 169
C. INFORMED CONSENT FORM .......................................................................... 174
D. DEMOGRAPHIC SURVEY .................................................................................. 178
E. FOCUS GROUP TIME REMINDER SHEET ......................................................... 179
F. PHONE CALL SCRIPT ........................................................................................ 180
G. TEXT MESSAGE SCRIPT .................................................................................. 181
H. NEWEST VITAL SIGN ......................................................................................... 182
I. REVISED NEWEST VITAL SIGN ....................................................................... 186
J. MA BMI LETTER ................................................................................................ 189
## LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Selected health literacy measures</td>
<td>151</td>
</tr>
<tr>
<td>2. Selected readability measures</td>
<td>152</td>
</tr>
<tr>
<td>3. Demographic characteristics of participants</td>
<td>153</td>
</tr>
<tr>
<td>4. SAM+CAM and readability of BMI letter and educational materials</td>
<td>154</td>
</tr>
<tr>
<td>5. Newest Vital Sign categories and scores</td>
<td>154</td>
</tr>
<tr>
<td>6. Parents’ reactions to 10 words for children’s excess weight</td>
<td>155</td>
</tr>
<tr>
<td>7. Mixed reactions to <em>obese</em> for describing children’s excess weight</td>
<td>156</td>
</tr>
<tr>
<td>8. Positive and negative experiences with health professionals</td>
<td>157</td>
</tr>
<tr>
<td>9. Initial reactions to the BMI letter</td>
<td>159</td>
</tr>
<tr>
<td>10. Mixed reactions to BMI screening in schools</td>
<td>160</td>
</tr>
<tr>
<td>11. Parents’ understanding of the BMI letter</td>
<td>161</td>
</tr>
<tr>
<td>12. Barriers to making changes</td>
<td>162</td>
</tr>
<tr>
<td>13. Participants’ emotional reactions to their child’s weight</td>
<td>163</td>
</tr>
<tr>
<td>14. Adults’ preferred weight terms based on the WPQ</td>
<td>166</td>
</tr>
</tbody>
</table>
**LIST OF FIGURES**

<table>
<thead>
<tr>
<th>Figure</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Distribution of participants' literacy skills based on the NVS</td>
<td>167</td>
</tr>
</tbody>
</table>
CHAPTER 1
INTRODUCTION

Childhood obesity is a significant and intractable public health problem in the United States. Nearly one-third of U.S. children are obese or overweight (Singh, Kogan, & van Dyck, 2010). In 2007, 16.4% were obese and an additional 15.2% were overweight. These statistics indicate that the prevalence of overweight has more than tripled over the past three decades (Singh et al., 2010). Prevalence of obesity-related comorbidities has also increased among children during that time period. Comorbidities seen more frequently in children include high blood pressure, accelerated development of atherosclerosis, type 2 diabetes, nonalcoholic fatty liver disease (NAFLD), polycystic ovary disorder, and disordered breathing during sleep (Daniels et al., 2009). In addition, childhood and adolescent overweight and obesity significantly increases risk for premature mortality and cardiometabolic morbidity in adulthood (Reilly & Kelly, 2011). Thus, novel public health approaches to effectively address the childhood obesity epidemic are urgently needed.

Numerous interventions have been assessed for their potential to impact the childhood obesity epidemic from the level of an individual to a national scale. In the field of public health, a novel intervention in the past decade is the practice of conducting body-mass index (BMI) screening in schools. This screening is followed by parent notification of student results in order to monitor changes in obesity prevalence and promote early adoption of healthy eating and physical
activity behaviors. In February 2009, Massachusetts began requiring measurement of height and weight and BMI/BMI percentile calculation for students in grades 1, 4, 7 and 10, followed by direct, confidential, and written notification to parents and provision of screening data to the state department of public health (Massachusetts Department of Public Health [MA DPH], 2009). As of 2010, 20 U.S. states required BMI or body composition screenings, with 13 requiring BMI screening specifically, and seven states requiring a fitness assessment including BMI or body composition (Linchey & Madsen, 2011). Nine additional states recommended BMI or body composition screening. Parent notification was required in nine of the 20 states that support either BMI screening (Arkansas, Illinois, Massachusetts, New York, Ohio, Pennsylvania, and Tennessee) or body composition screening (Alabama and Georgia). However, the extent of voluntary notification for parents in states that do not require it is unknown on a national scale (Linchey & Madsen, 2011).

Parents are typically notified by a letter sent home that informs them of their child’s weight status based on a BMI calculated during the school screening. This letter also provides brief nutrition and physical activity resources. In Massachusetts, school districts are required to notify parents prior to screening to allow them to opt out of the process for their children. However, little research directly addresses the question of whether the BMI letter is being used effectively to communicate with parents or promote positive behavior change. Because BMI notification is a public health policy that relies heavily on effective communication, research on health literacy skills of target groups is of particular
interest. Health literacy is a construct that describes an individual’s ability to use health information and navigate the health care system to make appropriate health-related decisions (Ratzan and Parker, 2000). Understanding a BMI report and using it to make decisions about a child’s health care are clearly relevant to health literacy. Thus, research about BMI communication with parents can be informed and enhanced by assessing the health literacy skills of its target groups. However, in the limited research on BMI notification to date, health literacy has not been considered. This thesis examines health literacy and nutrition, parents’ perception of children’s weight, parents’ weight-related communication preferences, and the ways in which parents conceptualize their children’s weight. Such a review demonstrates the rationale for a qualitative study of health literacy, weight-related language, the BMI letter, and conceptualization of weight among parents of obese children.
CHAPTER 2

PERCEPTION OF CHILDREN’S WEIGHT

Parents’ Perception of Children’s Weight

Any discussion of the ways in which adults conceptualize children’s weight can be informed by research that investigates parents’ perceptions of their child’s weight. This research topic has been addressed in a variety of settings, using primarily cross-sectional surveys, although some qualitative work has been conducted as well. Mothers, in particular mothers of toddlers and young children, have been studied most frequently and across a wide range of developed countries. The resultant body of literature illustrates the high degree of weight misperception that exists among parents, and even among health professionals in some cases. Although many factors have been associated with a parent’s tendency to inaccurately assess his or her child’s weight, there is relatively little qualitative research to explain the underlying reasons.

The prevalence of parents’ underestimation of their child’s weight status is high across a range of countries and children’s ages. For example, at an urban pediatric clinic with a mainly African American population (70%) in Rochester, New York, 31% of 193 parents of children 18 months to nine years of age underestimated their child’s weight status when asked to rate their child on a scale of “very underweight” to “very overweight” during a structured interview (Tschamler, Conn, Cook, & Halterman, 2010). Sixty-one percent of the parents were less than 30 years old. Based on their children’s BMI, parents were determined to have underestimated their child’s weight when they described a
normal-weight child as “very” or “a little” underweight or when they described an overweight child as “about right” or “a little” or “very” underweight. In addition, when compared to the parents who accurately rated their child’s weight status, parents of overweight children who underestimated their weight were significantly less likely to be concerned about their child’s weight (7.7% vs. 59%, P<.001) or believe their child was at risk for health or social problems related to their weight (4% vs. 47%, P<.001) (Tschamler et al., 2010).

Similarly, a survey of 96 predominantly white New Zealand children (aged 3 to 8 years) asked parents to classify their child’s weight as underweight, normal-weight, slightly overweight, or overweight (Miller et al., 2007). During a visit to a research center as part of a larger study, parents completed a questionnaire about their perception of the child’s weight. However, parents’ age and socioeconomic status were not reported. Researchers measured the children’s weights, heights, BMI, and waist circumference, and used DXA to measure fat mass, percent body fat, and lean mass. Thirty-one children had BMI values at or above the 85th percentile, but only seven of these children were rated slightly overweight or overweight by their parents. DXA measurements showed that these children had 83% more fat mass than children with BMI values below the 85th percentile (Miller et al., 2007).

This phenomenon of weight misperception that has been seen among parents may also exist, to a lesser degree, among children’s health care providers. Researchers at a pediatric gastroenterology clinic in Ontario, Canada administered a body size perception questionnaire containing a 5-point Likert
scale with word descriptions ranging from underweight to overweight and matched to body image figures for 91 parents of children aged 5 to 18 years, as well as their attending physicians. Among parents, whose demographic information was not reported, 44% underestimated their children’s body size using words and 47% did so using the figures (Chaimovitz, Issenman, Moffat, & Persad, 2008). Using the same scales, physicians underestimated 33% of children using both words and figures, and the physicians’ record of accuracy was significantly different from that of the parents in the case of both word descriptions (P=.00) and figures (P=.02) (Chaimovitz et al., 2008). However, physicians who regularly plot children’s BMIs on a standardized BMI-for-age chart utilize an objective method of assessment.

**Parents’ Perception of Children’s Weight-Related Health**

Parents’ recognition of a child’s actual weight status is closely tied to perception of their children’s weight-related health or health risk. In one study, 83 predominantly white parents accompanying their four- to eight-year-old children to a suburban New York pediatric faculty practice for well-care visits were surveyed. On a four-point Likert scale used to assess concern about health risks of excess weight, parents chose answers from “not at all concerned” to “extremely concerned.” A visual analog scale used to measure parents’ perception of their children’s weight consisted of a 10-cm line with one end labeled “extremely underweight” and the other end labeled “extremely overweight.” Parents were asked to mark the spot on the line that corresponded to their child’s weight status (Etelson, Brand, Patrick, & Shirali, 2003). When the
markings made on the visual analog scales were converted to percentiles for analysis, a parent’s perceived percentile that differed from the child’s actual BMI percentile by 30 or more points was categorized as inaccurate.

In addition, nearly 8 out of 10 (78%) parents surveyed in this study indicated that they would be “quite” or “extremely” concerned about excess weight in childhood. This rating was compared to the results of questions that elicited parents’ level of concern for other risky health behaviors (for example, having a smoker in the household, a history of many sunburns, or watching >20 hours of TV per week). The rating for excess weight was similar to attitudes about a child having a history of many sunburns. However, based on the visual analog scale results, fewer than half (48%) of parents accurately evaluated their child’s weight. Parents of children who were at or above the 95th percentile had an accuracy rate of 10.5%. In contrast, parents of children between the 25th and 49th percentiles had a 100% accuracy rate. All parents of children at or above the 75th percentile underestimated their child’s weight (Etelson et al., 2003). Based on these data, the authors concluded that parents understood the health risks associated with excess weight, but few acknowledged the existence of excess weight and thus possible health risks in their own overweight child (Etelson et al., 2003).

The question of exactly which weight-related health risks parents perceive as most important to their children also deserves attention. Fifty-five socioeconomically diverse parents of primary (all years) and secondary school (years 7 to 11) students across Australia who participated in focus groups
thought childhood overweight and obesity were issues of concern mostly because of the psychosocial consequences of teasing, social isolation, and poor self-esteem (Booth et al., 2009). Concerns about physical consequences tended to relate to an overweight child’s inability to perform physical activity rather than risk for serious health problems due to excess weight. However, this study included parents with a wide age range of children, and it did not specifically recruit parents of overweight children or determine how many participants had overweight children. Parents’ concern for psychosocial consequences was particularly pronounced among parents of female children, who expected the effects to worsen if a weight problem progressed into adolescence (Booth et al., 2009).

These research findings suggest that parents who accurately assess their children’s excess weight may be more likely to express concern for their child’s health; however, concerns about immediate impacts on psychosocial health may prevail over long-term risk for weight-related metabolic diseases (Booth et al., 2009). Family history of chronic weight-related diseases may also influence weight perception, as seen in a study of mothers (85% of participants) and fathers (12% of participants) of 125 overweight, 7-year-old children in Northern Finland (Vanhala, Keinänen-Kiukaanniemi, Kaikkonen, Laitinen, & Korpelainen, 2011). The study surveyed parent volunteers of children beginning schools within one city with a questionnaire asking parents to rate their child’s weight status on a five-point scale from underweight to heavily overweight. Of the parents surveyed, 42% of mothers (mean age=37 years) and 69% of fathers (mean
age=39 years) were overweight based on a BMI \( \geq 25 \) calculated from self-reported height and weight data. Compared to those without a family history of heart disease, parents of overweight children with a family history of heart disease were less likely to recognize their child’s overweight status (\( P=.045 \)). However, the authors did not discuss potential reasons for this unexpected finding.

**Factors Associated with Parents’ Perception of Children’s Weight**

The findings related to parents’ perceptions of their children’s weight and health prompt the question of how and why so many parents underestimate their child’s weight. Limited research addresses this question (Doolen, Alpert, & S. K. Miller, 2009). Quantitative and qualitative studies have identified factors associated with perception of children’s weight status. These factors relate to parent and family characteristics, such as culture/ethnicity, parents’ BMI, education, and numeracy skills; child characteristics, such as a child’s age, gender, and BMI; and societal factors, such as changing weight-related norms. Each of these is examined in more detail below.

**Parent and Family Characteristics**

**Culture/Ethnicity**

Interpretations of the disconnect between a children’s actual weight status and parent reports suggest that the underlying explanation includes cultural values about body size (Adams, Quinn, & Prince, 2005; Jain et al., 2001; Young-Hyman, Herman, Scott, & Schlundt, 2000). For example, four focus groups of a total of 32 mothers, fathers, and grandparents of children aged 6 to 10 years in
the Northern Mariana Islands illustrated the influence of Pacific Islander culture (Bruss et al., 2005). Thinness was described as a negative trait in this culture, particularly for children. Participants associated vegetable consumption with thinness and therefore had concerns about children eating too many vegetables (Bruss et al., 2005). Another study focused on cultural beliefs of Latina women (Contento, Basch, & Zybert, 2003). In this study of 187 low-income Latina women and their 5- to 7-year-old children in New York City, mothers were asked to select the body size line drawings that looked most like themselves and their child, as well as the drawings that resembled their preferred size and shape for each (Contento et al., 2003). In general, the women preferred a smaller body size for themselves compared to their current size. However, for both male and female children, mothers preferred their children at the 50th and 75th percentiles to have a larger body size, and mothers of children above the 97th percentile preferred their children to be only slightly smaller. The authors suggested that marital status and cultural subgroups of Latina women might influence their acceptance of a thin ideal for themselves but not for their children (Contento et al., 2003). Similarly, a study of 80 Hispanic mothers of kindergarten students in Mexican American neighborhoods of Chicago asked mothers interview questions drawn from validated surveys of acculturation and psychosocial family characteristics (Ariza, Chen, Binns, & Christoffel, 2004). Findings from this study suggested that mothers in the process of becoming acculturated may apply the U.S. thin female body ideal to themselves, but apply the “chubby” body ideal of their traditional culture to their children (Ariza et al., 2004).
Parents’ BMI

Some research also suggests a parent’s own overweight status influences their perception of their child’s weight. A study in England of 531 children aged 6 to 8 years and their mothers found that overweight mothers were 22% less likely to classify their child as overweight (95% CI: 0.79, 0.97) but 5% more likely to be concerned about future overweight (95% CI: 1.01, 1.10) (Parkinson et al., 2011). Among a purposive sample of largely homeless, low-income, minority mothers (n=257, mean age 35.5 years) living in shelters in Minneapolis, 20% of mothers could not give an estimate of their child’s weight (Dammann, Smith, & Richards, 2011). These mothers had a mean BMI (35.1 kg/m²) that was significantly higher than the BMI of mothers who did provide estimates (32.2 kg/m², P=.029). These findings suggest that heavier low-income mothers have a poorer awareness of their child’s weight status than those with lower BMIs (Dammann et al., 2011). In contrast, the nationally representative National Longitudinal Study of Adolescent Health (Add Health) of 15,483 teen (grades 7 to 12) and parent weight perceptions showed a role for parents’ obesity in accurate identification. Teens from families with an obese parent (based on self-reported height and weight) were more likely to be categorized as obese by their parents than teens from families with nonobese parents (15.4% vs. 4.5%, P<.0005) (Goodman, Hinden, & Khandelwal, 2000). Interestingly, in a study by Vanhala and colleagues (2011), overweight fathers (but not overweight mothers) were more likely to recognize their child’s overweight status than their normal-weight counterparts (P=.004). More research is needed to clarify the roles of parents’ gender, socioeconomic
status, and children’s age in the relationship between parents’ BMI and evaluation of their children’s weight.

**Parents’ Education**

A number of studies suggest parents with less education are more likely to inaccurately assess their child’s weight status than parents with higher levels of education (Baughcum, Chamberlin, Deeks, Powers, & Whitaker, 2000; Genovesi et al., 2005; Manios, Kondaki, Kourlaba, Vasilopoulou, & Grammatikaki, 2008). For instance, in a cross-sectional survey of 622 mothers of 23- to 60-month-old children visiting WIC clinics and pediatricians’ offices in Cincinnati and northern Kentucky, having no more than a high school education was associated with a failure to perceive one’s child as overweight (11% vs. 33%, P=.010). This association persisted after adjustment for low income, maternal obesity, age, and smoking, as well as the child’s age, race, and gender (adjusted OR: 6.2, 95% CI: 1.7, 22.5) (Baughcum et al., 2000). Parents’ education has also been associated with the likelihood of taking action to address a child’s excess weight. In another cross-sectional survey of a socioeconomically diverse group of parents with children aged 5 to 6 years (n=291 families) and 10 to 12 years (n=919 families) in Melbourne, Australia, the vast majority (89%) of parents of overweight 5- to 6-year-olds and the majority (63%) of parents of overweight 10- to 12-year-olds were unaware their child was overweight (Crawford, Timperio, Telford, & Salmon, 2007). Compared with those who had not completed high school, parents who had completed high school were 80% more likely to report taking action to prevent unhealthy weight gain in their children (OR 1.8, 95% CI: 1.2, 1.7). In
addition, parents with a college education were twice as likely to report taking these actions (OR 2.0, 95% CI: 1.3, 3.1) (Crawford et al., 2007).

**Parents’ Numeracy**

Related to education is numeracy, which has been defined in health contexts to mean “the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions” (Golbeck, Ahlers-Schmidt, Paschal, & Dismuke, 2005, p. 1). Low numeracy levels may influence a parent’s understanding of age- and sex-specific growth charts or BMI charts that health care providers use to communicate about a child’s anthropometric data. If parents do not fully comprehend the implications of their child’s plotted growth trajectory, or do not accept that the chart applies to their child, their perception of a child’s actual weight status may be inaccurate.

Research on caregivers’ understanding of growth charts has been conducted in developing countries, but the few studies done in the United States only examined how parents of overweight children use growth charts (Ben-Joseph, Dowshen, & Izenberg, 2007). Low-income mothers (n=18, 72% Black) of preschool children at risk for overweight were recruited on a voluntary basis from Ohio WIC clinics to participate in focus groups. Analyses showed that mothers would not use the growth chart to define their child as overweight because they disliked and distrusted growth charts (Jain et al., 2001). In another study with similar conclusions, focus groups (n=73) and follow-up interviews (n=18) were conducted in English and Spanish with minority parents of low socioeconomic
status with preschoolers living in Hartford, Connecticut (Goodell, Pierce, Bravo, & Ferris, 2008). The study found that parents did not consider growth charts to determine whether their child was overweight (Goodell et al., 2008). One mother described the growth charts as a “foreign language” (Goodell et al., 2008). Parents also thought the charts did not account for the individuality and uniqueness of their children (Goodell et al., 2008).

Qualitative studies conducted primarily with mothers enrolled in WIC identified additional lifestyle factors mothers use to gauge the appropriateness of their young child’s weight, often in lieu of growth charts. Mothers reported in focus groups that factors that signal children may be getting too heavy include poorly fitting clothes, problems with the child’s happiness or weight-related teasing, and the child’s level of physical activity and mobility (Hughes, Sherman, & Whitaker, 2010; Jain et al., 2001; Pagnini et al., 2007; Rich et al., 2005). Based on the mobility criterion, Jain et al. reported that focus group participants said they had never known a young child they thought was obese (2001), suggesting parents’ informal methods of weight assessment are less stringent than body-mass index (BMI) charts.

The question of whether growth charts are understood by parents has not been tested in U.S. populations, which is problematic because even relatively literate populations should not be universally expected to comprehend line graphs (Ben-Joseph et al., 2007). Likewise, parents’ understanding of the similar BMI charts used for assessing obesity risk has not been formally investigated (Ben-Joseph et al., 2007), with the exception of a recent study using a modified-
color coded BMI chart (Oettinger, Finkle, & Esserman, 2009). In this study, a convenience sample of 163 parents of children (aged 2 to 8 years) who were recruited from academic pediatric centers completed an “Understanding BMI” questionnaire containing questions based on a standard BMI chart, followed by the same questions based on a color-coded BMI chart. On the color-coded chart, the healthy weight range was shaded green, the overweight range was shaded yellow, and the underweight and obese ranges were shaded red. Participants assigned to the color-coded charts were more likely to answer the questions correctly than those using standard charts (mean 88% vs. 65% correct, p<.01). Parents with numeracy levels from kindergarten to fifth grade (as measured by the WRAT-3R) showed greater improvements in accuracy on the questionnaire when using the color-coded charts (51% correct using standard vs. 81% correct using color) than parents with numeracy levels at or above the high school level (89% vs. 99% correct). However, the “Understanding BMI” questionnaire is not a validated tool and may not reflect parents’ understanding in a clinical setting (Oettinger et al., 2009). Thus, more research in clinical and community settings is needed to clarify how parents’ numeracy skills influence BMI communication and understanding.

**Child Characteristics**

**Child’s Age**

Parents are often less likely to label a younger child overweight. For example, this tendency was seen in Norway among parents of children aged 4 to 11 years whose height-weight scale was above the 90th percentile.
groups about their experiences of parenting an overweight child, the parents described primary worries that centered on their child being stigmatized and teased due to their weight (Haugstvedt, Graff-Iversen, Bechensteen, & Hallberg, 2011). In general, parents were ambivalent about concern for overweight in younger children and were fearful about taking action that would worsen the child’s self esteem; they were most interested in protecting their young child from the “overreactions” of others (Haugstvedt et al., 2011). Likewise, in focus groups with 32 mothers of 2- to 5-year-old children across Australia, mothers voiced more concern about their young children being underweight than overweight and were unsure of whether “baby” or “puppy” fat was a problem (Pagnini, Wilkenfeld, King, M. L. Booth, & S. L. Booth, 2007).

In the study by Pagnini and colleagues, some mothers saw overweight as a bigger concern for older children because parents have less control over their weight-related habits (Pagnini et al., 2007). In addition, Crawford and colleagues (2007) found in a cross-sectional survey that parents taking action to prevent weight gain was more likely in 1210 parents of younger children when they were worried that their child may be overweight as an adolescent (OR: 2.2, 95% CI: 1.2, 3.8) or as an adult (OR: 2.1, 95% CI: 1.3, 3.6). Some evidence suggests the accuracy of parents’ weight reports improves as their child reaches adolescence. In a nationally representative study of 11,495 teens in grades 7 to 12 and their parents, weighted data from baseline youth and parent interviews conducted separately during the Add Health study asked parents to report yes or no to their adolescent having any of a number of health problems (Goodman et al., 2000).
Obesity was one health problem listed. In this study, a sizeable proportion (60.6%) of obese teens were correctly identified by parent report, but identification of overweight status was not evaluated.

**Child's Gender**

A child’s gender may also influence parents’ perception of their child’s weight status. A number of cross-sectional studies have found that parents are more likely to overestimate their daughter’s weight than their son’s, possibly reflecting social norms (Boutelle, Fulkerson, Neumark-Sztainer, & Story, 2004; Jeffery, Voss, Metcalf, Alba, & Wilkin, 2005; Manios et al., 2008; Vanhala et al., 2011). These differing perceptions also affect the weight control behaviors parents employ for children. More widespread use of strategies to prevent weight gain, particularly limiting fats, sugars, and “junk food,” has been reported among parents of 5- to 6-year-old girls as compared to boys (Crawford et al., 2007).

**Child’s BMI**

Inaccurate categorization of a child’s weight status is common among parents of overweight and obese children. However, within this group, odds of inaccuracy among parents appear to decrease as children’s BMI Z-scores increase (Manios et al., 2008; Maynard, Galuska, Blanck, & Serdula, 2003, Vanhala et al., 2011). In a study of 192 African American and Hispanic mothers with 3- to 5-year-old children enrolled in suburban Texas Head Start centers, mothers were asked to select the child figure silhouette that most closely resembled their child’s body size, as well as the figure they would most like their child to look like (Killion, Hughes, Wendt, Pease, & Nicklas, 2006). A significant
chi-square analysis ($\chi^2=4.91$, $P<.05$) suggested mothers of children at risk for overweight (85th-95th percentile) were more likely to be satisfied with their children’s body size compared to mothers of children who were overweight ($\geq 95$th percentile). This satisfaction may affect likelihood of labeling their child overweight or fat and explain the effect of increasing BMI Z-score on parents’ assessment of their child’s weight.

Societal Factors

Changing Weight-Related Norms

Decreases in the proportion of adults classifying themselves as overweight between the NHANES periods 1988-1994 and 1999-2004 provide evidence that weight-related norms are changing in the United States (Burke, Heiland, & Nadler, 2009). Thus, in explaining the observed disconnect between parents’ assessments of their child’s weight status and the child’s actual weight status, it has been suggested that parents fail to notice some excess weight in their children because it seems normal (Crawford et al., 2007). This conclusion was supported in findings from seven focus groups with mothers of children aged 2 to 5 years across Australia. Mothers in this study considered a child overweight based on comparison to other children their age (Pagnini et al., 2007), a method of assessment that would be affected by larger sizes in children “becoming increasingly normative” (Crawford et al., 2007).

Limitations and Future Research Needs

The body of research on how parents evaluate their children’s weight is extensive, but some limitations should be noted and addressed in future studies.
All research in this area appears to be cross-sectional and such designs cannot assess longitudinal changes in weight perception. Some of this research has been conducted with parents of children from wide-ranging age groups, such as 5 to 17 years old (Young, Schwartz, Monsur, West, & Neale, 2008), whereas other research has been conducted with parents of children from a more narrow age range, such as 24 to 59 months (May et al., 2007). Given the importance of a child’s age on the accuracy of parents’ weight assessments (Crawford et al., 2007; Haugstvedt et al., 2011; Pagnini et al., 2007), studies conducted separately with parents of children from more limited age groups may be more informative. Although one study suggested that mothers and fathers did not differ in their descriptions of a child’s body size (Holm-Denoma et al., 2005), research with fathers is limited. There is also a paucity of data examining the effect of a parent’s age on evaluations of their child’s weight.

Changing terminology and indicators of childhood overweight and obesity also complicate interpretations of the literature. Within the past decade, the Centers for Disease Control and Prevention (CDC) has shifted from identifying children at or above the 85th percentile on BMI charts as “at risk for overweight” to “overweight”; children at or above the 95th percentile are now classified as “obese” rather than “overweight” (Ogden & Flegal, 2010). Thus, it can be difficult to directly compare the findings of some older studies (e.g., Maynard et al., 2003; Myers & Vargas, 2000) with studies using the updated criteria for identifying overweight and obesity (e.g., Manios et al., 2008). International research often uses the International Obesity Task Force (IOTF) cutoff points for determining
childhood weight status. Such research has found an especially low rate of accuracy in parents’ assessments (1.9% and 17.1% for parents of overweight and obese children, respectively), which authors suggest could be related to the IOTF cutoffs classifying relatively more children as overweight (Carnell et al., 2005). In addition, conclusions of studies that directly measured child and parent BMIs may differ from those in which height and weight are reported by parents (Holm-Denoma et al., 2005) or teenagers (Goodman, Hinden, & Khandelwal, 2000). The latter studies are limited by the use of self-reported height and weight data.

In addition, the lack of a validated, standard methodology for measuring parents’ assessments of their children’s weight limits comparisons between studies. For example, one study asked mothers to complete the statement, “I feel that my child’s weight is …” by choosing one of the following: much higher than normal, higher than normal, normal, lower than normal, much lower than normal (Manios et al., 2008). Others have given options for underweight, normal weight, slightly overweight, and heavily overweight (Vanhala et al., 2011) or very fat, fat, normal, and thin (Hirschler, Calcagno, Clemente, Aranda, & Gonzalez, 2008) or for listing obesity as a health problem (Goodman, Hinden, & Khandelwal, 2000). Certainly, higher than normal, overweight, obesity, and fat could all have slightly different meanings for one parent or for entire populations. Words make a difference. In an infant development study of 93 mothers and 54 fathers (>95% white) of 3-year-old children, parents were asked to describe their child as thin, average, plump, or fat. Not one parent described their child as fat, but 20% of
girls and 18% of boys in the study were overweight (Holm-Denoma et al., 2005). Still other studies have used visual analog scales (Etelson et al., 2003) or silhouettes tested for cultural appropriateness in cognitive interviews (Killion et al., 2006) rather than words. Cognitive interviews are frequently used to understand how individuals attend to and process information to improve survey instruments (Carbone, Campbell, & Honess-Morreale, 2002) and may improve the validity of studies in this area of research.

Finally, the investigation of literacy, numeracy, and health literacy as factors that potentially impact how parents evaluate their children’s weight are very limited. Only one study in this area has addressed numeracy (Oettinger et al., 2009), and this was in relation to understanding of BMI charts specifically. No studies have investigated whether limited health literacy skills influence how parents perceive and conceptualize their children’s weight. Low health literacy levels could help to explain the observed associations between lower maternal education and misperception of their children’s weight (Baughcum et al., 2000; Genovesi et al., 2005; Manios et al., 2008). Given the numerical reasoning skills needed to understand BMI and percentiles, as well as the health literacy skills needed to negotiate interactions with child health care providers, future studies should examine how health literacy skills impact parents’ perceptions and communication preferences in this area.
CHAPTER 3

COMMUNICATION AND CONCEPTUALIZATION OF WEIGHT

Communication and Conceptualization of Adults’ Weight

Few studies have examined how adults conceptualize and prefer to communicate about their children’s weight. Relatively more work has been done with respect to adults’ weight and preferred communication approaches and terms to describe it, particularly in health care settings. An examination of this body of research will inform the discussion of children’s weight communication that follows.

Frequency of Weight Communication with Physicians

During visits with physicians, the frequency of weight loss counseling with overweight patients has been described as low (Anderson & Wadden, 2004). When it does occur, patients may be more likely to raise the issue (Scott et al., 2004). However, other qualitative research has found that when patients seemed to be reluctant to discuss weight management, it may be due to embarrassment or shyness and physicians should not assume their silence indicates a lack of desire to deal with the issue (Malterud & Ulriksen, 2010). In focus groups with 17 family physicians and internists (65% female, 59% white) about initiation of weight conversations in the clinical setting, a common approach among physicians raising the issue was to do a “noticing.” This technique involves looking at the patient’s chart, commenting on the fact that weight gain has occurred, and then initiating a discussion of diet and weight loss. In other cases, weight loss was linked to comorbidities (Alexander et al., 2007) and was
presented as a solution to avoid taking additional medications or insulin shots. In other words, it was a choice made by the patient to treat their condition by losing weight (Scott et al., 2004). In these cross-sectional studies, reasons for the weight conversation not being initiated were unexplored, aside from the speculation that weight is a sensitive topic. Therefore, longitudinal analysis of patient-physician weight communication is needed (Scott et al., 2004) to further explore these issues.

Much of the limited research on patient-physician weight communication has been based on focus groups or self-reports of encounters from either patients or physicians. In an interesting approach by Greiner and colleagues (2008), post-visit survey assessments of both parties were conducted to evaluate the extent to which 456 patients (62% female, mean age: 55.7±15.3 years) and 30 physicians (20% male, mean age: 42.7±10.5) agreed on whether the topics of weight, physical activity, and diet were discussed during routine visits. Patients had a mean BMI of 37.6±7.5 kg/m². Patients and physicians disagreed on weight, physical activity, or diet following 23% of office visits, and disagreed on two or more of the topics following 16% of visits; however, they agreed more often on the topic of whether weight was discussed as compared to diet or physical activity. Because physicians in this study reported discussion of weight issues more frequently than patients did, the authors suggested that physicians may not be assessing patients’ information needs and readiness for information and are therefore unable to tailor discussion content accordingly. Alternatively, physicians may need to provide more specific, detailed information in their
communication with patients about diet and physical activity (Greiner et al., 2008) or refer patients to a registered dietitian. Future research should examine the extent to which health literacy plays a role in this disconnect, as patient-provider interaction is a critical component of health literacy.

**Patient Preferences for Specific Weight-Related Language**

Cross-sectional survey research using the Weight Preferences Questionnaire (WPQ) developed by Wadden and Didie (2003) identified neutral terms such as *weight* that may be helpful in weight-related communications with adults (Table 14). This questionnaire reads:

> “Imagine that you are visiting your doctor for a check-up. The nurse has measured your weight and found that you are at least 50 lb over your recommended weight. The doctor will be in shortly to speak with you. Doctors can use different terms to describe weight. Please indicate how desirable or undesirable you would find each of the following terms if your doctor used it.” (p. 1141)

The terms were *fatness, obesity, large size, excess fat, weight, heaviness, BMI, excess weight, unhealthy body weight, weight problem, and unhealthy BMI*. Desirability is measured with a five-point Likert scale (1=very desirable, 2=desirable, 3=neutral, 4=undesirable, and 5=very undesirable). In one study with the first reported use of the WPQ, 219 obese men and women participating in randomized trials of obesity treatment, as well as 105 extremely obese women seeking bariatric surgery, were asked to rate the desirability of the 11 terms listed above for describing excess weight on the five-point Likert scale. Obese women rated the terms *fatness, excess fat, obesity* and *large size* as undesirable to very undesirable; the term *weight* was significantly more desirable (all P ≤ .001) than all other terms (Wadden & Didie, 2003). In addition, the terms *excess weight* and
BMI were rated neutral to undesirable. The obese men and extremely obese women in the study had similar preferences. The effect of word order was tested but not found to have a significant effect. Psychometric testing of the WPQ was reported in a recent study (Volger et al., 2011). The terms were reviewed for content validity by the authors, and same-day test-retest reliability coefficients for the terms were assessed in 30 obese volunteers. Five coefficients were >0.80, with the lowest being 0.70 (weight problem) and the highest being 0.93 (fatness) (Volger et al., 2011).

The WPQ has also been used with the addition of the phrase overweight status, which was not among the desirable choices for 143 predominantly female, overweight and obese patients (mean age: 46.8±12.5 years) at a managed care organization seeking treatment for weight loss (Dutton et al., 2010). Findings were similar to those of Wadden and Didie, but in this study a modified WPQ was also administered to a sample of 108 physicians on the faculty of a nearby medical school, who were asked to rate the likelihood that they would use each term in a clinical encounter to describe a patient’s excess weight. Physicians’ reported preferences for the weight terms were consistent with terms found desirable by study participants seeking treatment for weight loss (Dutton et al., 2010). However, these conclusions are drawn from self-reported preferences and not recordings of actual physician behavior in clinical encounters (Pollak et al., 2007; Pollak et al., 2010).

The studies by Wadden and Didie (2003) and Dutton et al. (2010) were recently replicated in a larger study of 390 obese adult primary care patients.
(mean age 51.5 years, 80% female, 38.5% African American) enrolled in a weight reduction trial and resulted in similar findings (Volger et al., 2011). Nearly all of the study participants (95%) had the equivalent of a high school degree, with 38% having a bachelor's degree or higher. The term fatness was rated as significantly more undesirable than all other terms (P<.001). Excess fat, large size, obesity, and heaviness were rated as significantly more undesirable than the remaining terms (including weight problem, BMI, and excess weight) (P<.001). Again, the term weight was most desirable. Because this study was larger, it was better suited than previous research for examining the effect of patient characteristics on preferences. No significant influence of gender, race/ethnicity, or BMI >40 was observed (Volger et al., 2011).

The study by Volger et al. added two supplementary open-ended questions to the WPQ asking participants to indicate the two words you would most want your physician to use and the two words you would least want your physician to use (not limited to those tested in the WPQ). Participants wrote in weight and weight problem, and fatness and obesity, respectively. Other terms considered desirable and not included in the WPQ included body weight, overweight, unhealthy weight, size, and health. Examples of undesirable write-in phrases included body fat, you are way too fat, and you are lazy. The results of this study also showed that obesity and fatness were rated slightly less negatively than in the first study by Wadden and Didie (2003). Although the populations surveyed differ, the authors speculated that the changes in ratings may be due to increased awareness of the obesity epidemic (Volger et al., 2011).
Other research in the United Kingdom found that 95% of primary care physicians (n=19, predominantly male and aged 40 to 49 years) in one study did choose the word *obese* as their preferred term for discussing weight with patients (Tailor & Ogden, 2009). Forty-seven percent of the physicians preferred the euphemism *your weight may be damaging your health*, which was the most popular choice. Interestingly, when presented with a vignette describing both options, a sample of 449 patients differed in their preference based on their own BMI. The vignette read, *Imagine that you are a patient who is experiencing joint pain and breathlessness. Your doctor weighs you and tells you that EITHER “you are obese” or “your weight may be damaging your health.”* (p. 261). Whereas the term *obese* was more upsetting to individuals who were not obese, obese patients said they would be more upset by the use of the euphemism. The authors suggested that this preference for *obese* could be due to patients liking medical terms to describe their condition, which do not make them feel that the problem was brought on by themselves (Tailor & Ogden, 2009). Thus, it is possible that the use of the term *obese* in health communications may not have the expected negative emotional impact if it is framed as a medical diagnosis. This finding differs from previous research conducted in the United States using the WPQ (Dutton et al., 2010; Volger et al., 2011; Wadden & Didie, 2003). It is possible that sociocultural differences between the countries affect desirability of the term *obese*, even when used in a medical context.

While these findings are useful for tailoring weight-relating communications to include terms such as *weight*, *weight problem*, and/or *BMI* (if
understood), all study populations (with the exception of Tailor & Ogden, 2009) were recruited from individuals seeking weight loss treatment, who may differ on important characteristics from individuals not seeking weight loss treatment. Conversely, obese individuals who are not actively seeking weight loss treatment may be the individuals with whom physicians need to start a weight conversation (Wadden & Didie, 2003). In a recent focus group study of overweight (n=32) and obese (n=18) African American women who stated an interest in losing weight, obese was viewed as an insult and was not a word participants used to describe themselves (James, Pobee, Oxidine, Brown, & Joshi, 2012). However, women in this study were not specifically asked which words they would prefer that a health professional use to describe their excess weight.

Further, more research has been done with obese than overweight individuals, who may prefer different terminology and must be engaged in conversation to avoid progression to obesity and its associated health complications. Preferences for particular terminology and/or communication approaches may differ in real-life clinical encounters, compared to those simulated using vignettes and questionnaires (Tailor & Ogden, 2009), so these findings should be used as the basis for interventions testing communication styles in health care settings.

Little qualitative research has been done on adult patient perspectives and preferences for weight-related communication in healthcare settings. In a recent study using semi-structured interviews, 34 overweight and obese (BMI ≥ 27 kg/m²) men and women in their mid-to-late 30s and 50s from the United Kingdom
were recruited from a community cohort participating in a longitudinal health study and were not necessarily actively seeking weight loss treatment (Gray et al., 2011). Thus, the researchers encountered more diversity in terms of subjects’ motivation to lose weight, and this difference informed analysis of the study’s findings. Participants were categorized as appearing motivated or unmotivated to lose weight (or motivation unclear) based on a reading of the transcripts and noting when individuals mentioned their weight loss or their intent to lose weight with specific plans. Many participants did not like the social/popular use of the term *obese*, which they felt connoted a moral judgment, or the term *fat*. However, young men who were motivated to lose weight reported that use of *fat* was acceptable as banter in social situations. This preference for the term *fat* over *obese* has also been found in other qualitative research with a broad sample of obese adults (aged 16 to 72 years) (Thomas, Hyde, Karunaratne, Herbert, & Komesaroff, 2008). Among adults in other focus groups, the term *fat* was seen as too personal and judgmental for use even by health professionals (Gray et al., 2011).

However, participants in the study by Gray et al. (2011) were split on whether or not the term *obese* should be used by health professionals, as some participants—in particular those who were younger adults—recognized its use as a medical diagnostic term, which has been reported in other research in the UK (Tailor & Ogden, 2009). For example, some participants were more comfortable with the phrase *clinically obese* than *obese*, which again suggests that putting obesity into the context of medical problems can facilitate productive discussion.
about strategies for weight loss (Gray et al., 2011). It is important to note, however, that some older participants, particularly those categorized as unmotivated to lose weight, didn’t agree that health professionals should use the term *obese* and thought it would be unhelpful and insulting. Although preferred over many other terms considered undesirable in other research (Volger et al., 2011), men who were unmotivated to lose weight also did not like use of the term *BMI* because they did not always consider it to be a valid indicator of excess fat. These men spoke of fitness and physical activity regimens being part of their identity, which made them question the utility of BMI as an indicator of excess fat (Gray et al., 2011). These perspectives regarding the descriptor *BMI* are important to consider in any future research on communication about individuals’ BMIs.

One concept of interest explored by Gray and colleagues (2011) but not previous research is that terms individuals found most acceptable to describe their excess weight were not always consistent with terms they reported would be most likely to motivate weight loss. Terms chosen as motivational included *unhealthy BMI, high BMI, and unhealthily [sic high body weight]*, which were considered professional and clearly defining a health problem. *Overweight* was not an effective motivator because many participants felt comfortable describing themselves as overweight (Gray et al., 2011). Based on these findings, it appears that terms with which patients are comfortable, such as those identified as preferred from the WPQ, may not be effective motivators. However, it is possible that these comfortable terms may be useful when health professionals
initiate a conversation about a sensitive topic with an overweight or obese patient for the first time. Future qualitative research is needed to understand the optimal use of and differences between language that is acceptable, understandable, and motivational for overweight and obese individuals who may or may not be actively seeking weight loss treatment.

**Communication and Conceptualization of Children’s Weight**

In general, less research has been done with parents regarding communication about their children’s weight than about their own weight. Communication with parents/caregivers (hereafter referred to as parents) about their child’s excess weight may be influenced by a variety of factors: parents’ education, cultural background, concern over stigmatization and bullying, use of emotionally-loaded language, underestimation of their children’s weight status, and health professionals’ display of concern when discussing the problem (Mikhailovich & Morrison, 2007). Even in conversations with physicians, parents may feel their child’s weight is their responsibility alone and something for which they could be blamed (Edmunds, 2005).

Culture may play a particularly important role in such communication. In one study, interviews were conducted with 446 ethnically diverse parents of overweight children (aged 2 to 12 years) attending one of 14 locations of a group medical practice in the greater Boston area (Taveras, Gortmaker, Mitchell, & Gillman, 2008). Compared to white parents, African American (OR: 2.55; 95% CI: 1.18, 5.51) and Hispanic/Latino (OR: 2.78; 95% CI: 1.27, 6.10) parents were more likely to rate the quality of nutrition advice received from pediatricians as
poor or fair (Taveras et al., 2008). In another study, 12 Latino fathers and 12 Latina mothers in focus groups voiced a need for health providers to acknowledge the challenges they face, such as meal preparation and finding safe physical activity opportunities, in order for weight-related communication to be effective (Snethen, Hewitt, & Petering, 2007). Encountering racism in neighborhood play areas and the costs associated with organized sports were specific barriers to children’s physical activity mentioned (Snethen et al., 2007). All of these issues should inform an analysis of the language that is most preferable and effective to use when communicating with parents about their children’s weight. As noted earlier, language that is preferable and language that is effective may not be the same.

**Preschool-Age Children**

Research with parents of preschool-age children has generally shown that communication about a child’s excess weight is hampered by parents’ reluctance to label children as overweight or obese because they are still growing. In three focus groups held with a total of 18 predominantly Hispanic, Medicaid-insured mothers to evaluate a primary care obesity prevention pilot program for preschool-age children, participants were pleased with the incorporation of nutrition into the office visit but resistant to the diagnosis of obesity for their child (McKee, Maher, Deen, & Blank, 2010). Parents cited the child’s size as being in their nature and said the physicians’ expectations were wrong (McKee et al., 2010). For example, one parent said, “He’s been off that baby chart from the day he was born” (p. 252). Similarly, focus groups held with 43 Latina mothers and
grandmothers of preschool children aged 2 to 5 years recruited from WIC sites found that mothers had difficulty acknowledging overweight in their children and felt that weight and health were poorly associated (Crawford et al., 2004). Women in this study described health as being related to children’s happiness, being part of a loving family, and exercise and play habits; thinness could mean poor health. Future research should investigate the extent to which parents’ health literacy levels influence such health beliefs and seek to optimize communications around improving nutrition and physical activity in spite of their beliefs. In addition, research in this area with fathers and members of other minority groups is limited.

Older Children and Adolescents

Despite the need for physician-parent communication regarding children’s weight, little research has explored parents’ preferred language for communicating about their children’s weight status. Rather than usual clinical terms like obesity, ten female maternal and child health nurses from a convenience sample in Melbourne, Australia said in interviews that they tried to present information about a child’s weight sensitively by using the words large, heavy, big, off the graph, out of the recommended range, or put on a lot of weight (Edvardsson, Edvardsson, & Hörnsten, 2009). The word overweight was considered a more sensitive way to convey the same information as the word obese. However, to date only two studies have been designed to directly test the acceptability of some of these words with parents using surveys (Eneli, Kalogiros, McDonald, & Todem, 2007; Puhl, Peterson, & Luedicke, 2011).
Parents seeking care for their children in a general practice clinic in Michigan were asked to complete a short survey that included the question, “Which word do you think physicians should use to describe their concerns about a child’s weight?” Parents chose from fat, overweight, obese, gaining too much weight, too heavy, and does not matter (Eneli et al., 2007). Parents’ self-reported height and weight were used to determine their own weight status. Child ages were not reported. Of the 292 parents (90% women, 53% with a BMI > 25, 65% white, and 45% with a child on Medicaid) who completed the survey, 51.1% preferred gaining too much weight. Only 25.9% preferred overweight. This difference was statistically significant (P < .001) and the preference was similar among overweight and obese parents (Eneli et al., 2007). The authors suggested gaining too much weight was less stigmatizing to parents because it does not label the child; rather, it describes a process of weight gain they can address by making changes (Eneli et al., 2007).

Some of the terms in the study by Eneli and colleagues (2007) were tested more recently in an online survey of 445 American parents (70% white, 59.6% female) of 2- to 18-year-old children (Puhl, Peterson, & Leudicke, 2011). Parents’ weight distribution reflected national averages; according to their self-reported heights and weights, 38% of parents were normal weight, 32% were overweight, and 26% were obese (Puhl et al., 2011). The online survey used a modified Weight Preferences Questionnaire (Wadden & Didie, 2003) to ask parents about terms doctors might use in describing their child’s weight. Ten weight terms were presented in random order and rated on a five-point scale.
(1=not at all, 5=very) for desirability and the degree to which the terms were stigmatizing, blaming, or motivating to lose weight. The terms were extremely obese, high BMI, weight problem, unhealthy weight, weight, heavy, obese, overweight, chubby, and fat. Weight was rated most desirable (mean rating: 3.65, 95% CI: 3.53, 3.77), followed by unhealthy weight (3.42, 95% CI: 3.29, 3.56), high BMI (3.35, 95% CI:3.21, 3.48), and weight problem (3.06, 95% CI: 2.93, 3.19). Chubby (mean rating: 2.16, 95% CI: 2.04, 2.28), obese (2.11, 95% CI:1.98, 2.24), extremely obese (1.88, 95% CI: 1.76, 2.01), and fat (1.78, 95% CI: 1.67, 1.89) were rated most undesirable. These four undesirable terms were also rated most stigmatizing and blaming. Conversely, terms rated most motivating to lose weight were unhealthy weight (mean rating: 3.60, 95% CI: 3.48, 3.72), weight problem (3.28, 95% CI: 3.16, 3.40), overweight (3.26, 95% CI: 3.14, 3.39), and weight (3.03, 95% CI: 2.92, 3.15). Future qualitative research should explore reasons underlying parents' preferences.

Little research has assessed adolescent preferences for terms used in communication about their own weight. The “Weight and its Relationship to Adolescent Perceptions of their Providers” (WRAP) survey was administered to 62 severely overweight (BMI 38.9 ± 8.4) and 29 normal weight (BMI 22.5 ± 4.0) male and female adolescents (age 13.9 ± 1.7 years; 50% Caucasian, 47% African American, 3% Hispanic). Nearly half (47%) of participants identified overweight as the term most preferable to describe adolescents with a weight problem (Cohen, Tanofsky-Kraff, Young-Hyman, & Yanovski, 2005). Overweight was chosen more frequently than the following terms (in descending order of
popularity): *obese, big boned, big, heavy, large, fat, husky,* and *big bodied* (Cohen et al., 2005). The exact wording of the question used to elicit their preferences was not reported. These choices reflect the literature on adults’ preferences for neutral terms such as *weight* and *overweight* (Volger et al., 2011; Wadden & Didie, 2003); however, the fact that *obese* was not among the least preferred terms was unexpected. Future research should investigate whether the fact that adolescents do not dislike *obese* is related to a generational shift. Other qualitative research suggests that rather than using any direct terms for describing obesity, adolescents would prefer to focus on behaviors and actions that affect weight, such as healthy eating, when communicating about weight with their parents (Shrewsbury et al., 2010).

**Hurtful Communication**

Certainly, not all communication about excess weight in childhood and adolescence is productive; hurtful comments can even come from family members. For instance, a longitudinal survey of 2,287 racially and socioeconomically diverse young adults (through high-school age) documented the occurrence of hurtful weight-related comments from family (reported by 35.9% of females and 22.8% of males) and significant others (21.2% of females and 23.8% of males) (Eisenberg, Berge, Fulkerson, & Neumark-Sztainer, 2011). In addition, a survey of 356 adolescent girls who took part in a school-based physical activity intervention found that frequency of parent weight talk, such as a mother encouraging her daughter to diet, was associated ($P$ for trend=.048) with unhealthy weight control behaviors and was not associated with any positive
outcomes (Neumark-Sztainer et al., 2010). Thus, parents can help their children with both healthy weight management and healthy body image attainment by being a positive role model, creating a healthy environment in the home, focusing on overall health more than weight, and supporting their children to improve communication (Neumark-Sztainer, 2005). These considerations are important for needed future research to develop strategies that communicate a child’s weight status to their parents, without prompting counterproductive behaviors.

**Approaches to Communication in Clinical Settings**

In clinical settings, physicians and other health care providers have adopted a variety of approaches to communicating with parents about their children’s weight. Although publication of pediatric practice guidelines has helped raise awareness of the recommendation to calculate BMI percentile, only 52% of pediatricians reported doing so for children older than two years in a national survey of American Academy of Pediatrics (AAP) members (n=677). In a survey of American Academy of Family Physician (AAFP) members (n=445), a similar percentage (45%) reported that BMI percentile was calculated at most or every well visit for children older than two years (Sesselberg, Klein, O’Connor, & Johnson, 2010). A survey of more than 8,000 adolescents (aged 14 to 18 years) seen for primary care well visits found that counseling regarding weight and healthy eating occurred in about 80% of visits (Klein et al., 2006), suggesting weight may be addressed more regularly as children get older. Documented approaches to improving physician-family communications about BMI and weight include tools to direct questioning about nutrition and physical activity behaviors.
(Woolford, Clark, Ahmed, & Davis, 2009) and improve discussion of BMI with color-coded charts (Gilbert & Fleming, 2007; Oettinger et al., 2009; Perrin et al., 2010). Another newer approach is the application of motivational interviewing for pediatric and adolescent obesity (Pollak et al., 2009; Resnicow, Davis, & Rollnick, 2006), which has been shown to be effective in more extensive research with adults (Armstrong et al., 2011; Pollak et al., 2007; Pollak et al., 2010; Pollak et al., 2011).

**Summary of Findings**

In conclusion, few studies have examined how adults conceptualize and prefer to communicate about their children’s weight. Relatively more work has been done with respect to adults’ weight. Research using the Weight Preferences Questionnaire with overweight and obese adults shows that words such as *weight, BMI, excess weight, weight problem* are most preferred and words such as *fatness, excess fat, large size, and obesity* are least preferred (Dutton et al., 2010; Volger et al., 2011; Wadden & Didie, 2003). Only two surveys done with parents have investigated preferences for weight terms used to describe children. In one study, *gaining too much weight* and *overweight* were chosen most frequently (Eneli et al., 2007). In the largest and most recent study, the words *weight, unhealthy weight, high BMI, and weight problem* were most desirable (Puhl et al., 2011). Future qualitative studies can examine the reasons underlying parents’ preferences and explore implications for respectful, effective BMI notification practices.
CHAPTER 4
COMMUNICATING CHILDREN’S WEIGHT WITH THE BMI LETTER

Research in clinical settings has focused on individualized, interpersonal approaches to communicating with parents about children’s weight. A public health approach adopted widely in recent years is BMI screening in schools followed by parent notification of results, typically in the form of a letter. Screening for BMI has been recommended by the Institute of Medicine (IOM) for addressing the childhood obesity epidemic (Koplan, Liverman, & Kraak, 2005). In February 2009, Massachusetts began requiring measurement of height and weight and BMI/BMI percentile calculation for students in grades 1, 4, 7 and 10, followed by direct, confidential notification to parents and provision of screening data to the state department of public health (Massachusetts Department of Public Health [MA DPH], 2009). The MA policy is intended to encourage discussions between families and health professionals about the child’s growth and development (MA DPH, 2009).

As of 2010, 20 states mandated BMI or body composition screenings; 13 require BMI screening specifically, and seven require a fitness assessment including BMI or body composition (Linchey & Madsen, 2011). Nine additional states recommended BMI or body composition screening. Parent notification is mandated in nine of the 20 states that require either BMI screening (Arkansas, Illinois, Massachusetts, New York, Ohio, Pennsylvania, and Tennessee) or body composition screening (Alabama and Georgia). However, the extent of voluntary
notification in states that do not require it is unknown on a national scale (Linchey & Madsen, 2011).

Despite its widespread adoption, relatively little research has been done to optimize weight-related communication during the parent notification phase of BMI screening programs—when letters are sent home to inform parents of their child’s results—or to collect outcomes data. In particular, no studies have evaluated the new Massachusetts BMI screening policy. In addition, BMI screening parent notification programs have been critiqued for relying on BMI as a predictor of excess adiposity and future health risks (Freedman & Sherry, 2009). A high BMI-for-age has been found to have a 70% to 80% sensitivity for identifying excess body fat and is a highly specific (95%) indicator, but this may vary among white, Black, and Asian children (Freedman & Sherry, 2009). In addition, BMI performs better in identifying body fatness among obese children than in overweight children (Freedman & Sherry, 2009). In one study, only 18% of the 200 overweight children measured had an elevated level of percent body fat, compared to 77% of the obese children (Freedman et al., 2009). BMI notification programs have also been criticized for a lack of evidence to show efficacy as an intervention for reducing childhood obesity (Cogan, Smith, & Maine, 2008; Soto & White, 2010) and the potential risk for disordered eating behaviors and heightened body dissatisfaction (Cogan et al., 2008; Ikeda, Crawford, & Woodward-Lopez, 2006; Portilla, 2011). Examining research on parent and student reactions to BMI screening and notification programs can
help elucidate future research needs in this area to improve communication strategies.

**Communicating with Parents about BMI in Schools**

Research on BMI notification programs has identified some preferences of parents with respect to message delivery and message content. Such research has also characterized some impacts on parents’ assessment of their child’s overweight status and behavior changes. For example, some survey and focus group research suggests parents’ responses to the BMI letter are more likely to be positive if the child is of normal weight (Kubik, Fulkerson, Story, & Rieland, 2006) or the screening program employs an active consent process in which parents must agree to their child’s participation (Harris & Neal, 2009), but both of these factors warrant further research.

There is a strong consensus that parents prefer results not be shared with students in schools and that communication be done via mail (Harris & Neal, 2009; Kubik, Story, & Rieland, 2007; Murphy & Polivka, 2007; Stalter, Kaylor, Steinke, & Barker, 2011) rather than sent home with students, which can increase costs for schools but also ensure confidentiality. There is also some evidence that delivery by mail is more effective in prompting parents to read the letter (Kaczmarski, DeBate, Marhefka, & Daley, 2011). In terms of message content, 22 parents recruited from West Virginia schools who participated in focus groups have expressed a desire for a clear statement of the findings and information about good nutrition for their child (Harris & Neal, 2009). Other focus groups involving a convenience sample of 71 parents (90% female, 96%
Caucasian, and 50% with college degrees) in two suburban Minnesota schools revealed that the preferred message content was characterized as a straightforward letter that describes BMI, the child’s measurement, and a recommendation to follow-up with a health care provider if concerned rather than specifically calling the child overweight and telling the parent what to do (Kubik et al., 2007). Participants in this study also suggested that the letter should focus on adopting healthy habits for the entire family.

Research is mixed on questions of whether BMI letters change parents’ perceptions of their child’s weight and affect their behaviors or intention to change behaviors. In Arkansas, parents of overweight public school children were surveyed by telephone about their evaluation of their child’s weight status before (n=1,551; 81% White, 15% African American) and one year after (n=2,508; 82% White, 15% African American) BMI screening and notification practices were initiated. At baseline, 60% of parents underestimated their overweight child’s weight, and underestimation was twice as likely in African American parents as compared to white parents. After implementation of the screening program, accuracy improved but not significantly (53% underestimation, P<.09), with significantly greater improvements among African American parents than white parents (change from 30% to 44% accuracy, P<.0001) (West et al., 2008). It is possible that viewing trends in a child’s BMI over time may improve parents’ understanding of their child’s weight status, but this has not been investigated as part of the school BMI notification process. Policy makers involved with the Arkansas program hope to report current BMI
results linked to prior years’ results for children in the future, to show trends in weight status classification (Justus, 2007). Parents of children in Arkansas public schools voiced a preference for such a longitudinal format in focus groups conducted in 2007, but demographic information for participants was not reported (Thompson & Card-Higgins, 2009).

Linking BMI screening with other health indicators could influence behavior change. In West Virginia, telephone interviews were conducted with parents of fifth-grade children identified as “at risk” (based on cholesterol levels or acanthosis nigricans [AN], an indicator of insulin resistance) 4 to 6 weeks after a school-based cardiovascular risk screening program including BMI notification (Harris & Neal, 2009). These interviews revealed that a moderate proportion of parents had made changes in their child’s diet, physical activity, and/or health care (40%, 34%, and 12%, respectively) after receiving the results, but the specific changes parents made were not reported. No significant increase in the accuracy of parents’ assessments of their child’s weight was observed, compared to pre-intervention levels (P>.05) (Harris & Neal, 2009). This lack of increase may be related to the fact that this unique intervention included screening for a variety of health-related factors, such as AN and cholesterol levels, which could have drawn parents’ attention away from body weight (Harris & Neal, 2009).

To investigate changes in parents’ intent to modify behaviors affecting their child’s weight, predominantly female (90%), highly educated (87% post-high school) parents (n=790) from four Minnesota elementary schools who received
letters with their child’s BMI results were surveyed (Kubik, Fulkerson, Story, & Rieland, 2006). Interestingly, very few parents who received the BMI letter and reported concern about their child’s weight planned to follow up with health care services (8%) or make dietary changes (<8%). Conversely, Johnson et al. (2009) found that in a Florida school district that had recently implemented BMI notification, 50 parents (64% white, 27% African American) randomly selected for an interview were more likely to recall receiving the letter if their child’s (grades K to 8) weight status was not within the normal range (underweight, overweight, or obese) as compared to parents with a child whose weight status was normal (75.6% vs. 54.9%, P=.002) (Johnson et al., 2009). This recall of abnormal weight status predicted concern about the child’s weight and discussion of the results with a health care provider (60% and 44% of parents with children of abnormal weight, respectively). Recall of overweight status was also predictive of parents who made changes to their child’s diet and physical activity (62.5% and 55% of parents with overweight children, respectively) (Johnson et al., 2009).

**Student Perspectives on BMI Communication in Schools**

Compared to research with parents, less work has been done to examine student perspectives on BMI screening and letters. A cross-sectional study of 852 ethnically diverse fifth- to eighth-grade students that involved a self-administered questionnaire immediately following school-based weight screening found that more overweight students (38.1%) reported being uncomfortable with the weight screening than healthy weight students (8.1%) (P<.001) (Kalich et al., 2008). However, weight-related teasing does not appear to increase during the
two years that follow screening. A study of random cross-sectional statewide telephone surveys with parents and adolescents conducted before and during the two years following initiation of the school-based BMI screening in Arkansas did not find a significant change in rates of weight-based teasing (Krukowski et al., 2008), which has been associated with low body satisfaction, low self-esteem, high depressive symptoms, and suicidal ideation and attempts (Eisenberg, Neumark-Sztainer, & Story, 2003). Similar research on school-based screening programs incorporating parent notification in London did not find a difference in rates of weight-based teasing (Grimmett, Croker, Carnell, & Wardle, 2008). However, this study was conducted only six weeks before and four weeks after parent notification occurred (Grimmett et al., 2008). Student reactions to the actual content of letters, if shared by the parents, do not appear to have been assessed in any research to date.

**Experimental Research on BMI Communication in Schools**

Research employing an experimental design may help to resolve some of the questions about effects of BMI communication outlined above, but such research is limited to two studies. In a quasi-experimental intervention study, families (n=1131) of ethnically diverse students from four urban elementary schools measuring height and weight were randomly assigned to a personalized weight and fitness health report card intervention (PI; n=481), a general information intervention (GI; n=451), or a control group (CG; n=199). (Chomitz, Collins, Kim, Kramer, & McGowan, 2003). Data from telephone interviews conducted with parents from the 399 families revealed that the intervention
parents (PI and GI) were significantly more likely to correctly identify their children’s weight status than control parents (44% and 41% vs. 23%, respectively, P=.02). PI parents were also significantly more likely than other parents to plan weight-control activities (seeking medical help or making diet or physical activity changes) (P<.001). However, the intervention materials provided in the mailings did not appear to impact families’ practice of recommended behaviors, including limiting TV time, increasing physical activity, and increasing fruit and vegetable intake (Chomitz et al., 2003).

Recently, in a natural experiment, Madsen (2011) assessed whether optional letters used to notify parents of BMI screening results for fifth-, seventh-, and ninth-grade students (n=6,967,120) in California public schools from 2001-2008 impacted BMI z-scores measured two years later. Compared with students whose parents were not notified of their BMI status, BMI notification in fifth and/or seventh grade did not significantly impact BMI z-scores two years later (95% CI, -0.03 to 0.01 BMI Z-score units). It is possible that some school districts’ notification methods were more effective than others; however, these potential differences were not investigated in Madsen’s study. Further research of this type should investigate whether the letters may be more effective in younger children, as well as whether an enhanced notification program with additional resources for parents is more effective in reducing weight.

**Need for Qualitative Research on BMI Communication in Schools**

Further qualitative research is indicated to explore underlying factors that impact the success of BMI notification in changing parents’ perceptions and
behaviors, as well as the acceptability of the letter to parents. To date, some studies have included formative qualitative research to develop parent notification materials (Chomitz et al., 2003; Harris & Neal, 2009; Kubik, Fulkerson, Story, & Rieland, 2006; Kubik, Story, & Rieland, 2007; Thompson & Card-Higginson, 2009); however, more in-depth examination of language preferences is needed. In particular, the role of culture in shaping communication about BMI has not been explored in depth. Because culture influences health perceptions and practices, and because the prevalence of obesity is increased among nonwhite children (Ogden et al., 2006), cultural considerations are essential in the planning of message delivery in BMI parent notification programs (Fitzgibbon & Beech, 2009).

**Summary of Findings and Research Needs**

Childhood obesity is among the most significant public health problems in the United States (Singh et al., 2010). A novel intervention targeting childhood obesity is the practice of BMI screening in schools, followed by parent notification of student results, which is being adopted by a growing number of states. However, little research directly addresses whether the BMI letter is being used effectively to communicate with parents or promote positive behavior change. Furthermore, in this limited research to date, health literacy has not been considered. Health literacy is most commonly defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Ratzan and Parker, 2000). Understanding a BMI report and using it to make decisions
about a child’s health care are clearly relevant to health literacy and numeracy. Thus, research about BMI communication with parents can be informed and enhanced by assessing the health literacy skills of its target groups.

A related issue in which health literacy may play a role is parents’ assessment of their children’s weight and health. Inaccuracy in parents’ evaluations of children’s weight status is high across a range of countries and children’s ages (Chaimovitz et al., 2008; Etelson et al., 2003; Miller et al., 2007; Tschamler et al., 2010). Some factors associated with parents’ inaccurate perceptions of their children’s weight include culture/ethnicity; parents’ BMI, lower education, and lower numeracy; children's younger age, male gender, and lower BMI; and changing weight-related norms. However, the ability to draw conclusions from this body of research is limited by varying age ranges used across studies, a lack of research with fathers, changing terminology to categorize childhood overweight, and the lack of a validated, standard methodology for assessing perceptions. In addition to perceptions, parents’ preferences for language to discuss their children’s weight have been evaluated. In general, the terms obese and fat are among the least popular for use with adults, adolescents, and children (Dutton et al., 2010; Eneli et al., 2007; Puhl et al., 2011; Volger et al., 2011; Wadden & Didie, 2003), but obese may be acceptable to some individuals when it is framed as a medical diagnosis (Gray et al., 2011; Tailor & Ogden, 2009).

Considerations of health literacy, parents’ perceptions, and weight language should all inform an approach to qualitative evaluation of the BMI letter.
Despite its widespread adoption, relatively few studies have focused on optimizing weight-related communication during the parent notification phase of BMI screening programs or collecting outcomes data. Research is mixed on questions of whether BMI letters change parents’ perceptions of their child’s weight and affect parents’ own behaviors or their intention to change behaviors. Rigorous use of experimental designs is needed to address questions about the effects of BMI communication, but to date only two such studies were found in the literature (Chomitz et al., 2003; Madsen, 2011). Experimental studies may assume that changes in children’s weight can be attributed to the BMI letter in particular, despite the large number of factors that affect children’s weight at any given time. Qualitative studies are needed to clarify how and why parents’ evaluations of their children’s weight and parents’ behaviors may—or may not—change in response to a BMI letter. Although many school districts are using a BMI letter to notify parents, variability in communication strategies may have contributed to the inconsistent research findings. Qualitative research can also explore in depth the underlying factors, such as culture, that impact the acceptability and success of BMI notification in changing parents’ perceptions and behaviors.

**Need for Investigation of Health Literacy**

One important factor that has not been studied in relation to communicating with parents about their child’s BMI is health literacy. Low health literacy in adults negatively impacts understanding of preventive care information (Sanders, Shaw, Guez, Baur, & Rudd, 2009). Previous research in adults has
also demonstrated a connection between low health literacy skills and poor weight management behaviors (Huizinga et al., 2009; Rothman et al., 2006; Zoellner et al., 2011), and a parent’s health literacy level has been shown to influence other child health outcomes, such as glycemic control in children with type 1 diabetes (Hassan & Heptulla, 2010; Janisse, Naar-King, & Ellis, 2009). Further, some evidence suggests that attention to health literacy needs could improve the efficacy of interventions to reduce BMI (Cluss, Ewing, Long, Krieger, & Lovelace, 2010). For example, a pediatric obesity intervention was adapted for low-literate, low-income families using low-literacy materials; telephone, mailed, and in-person support; and a clear focus on decreasing high-calorie foods and sedentary behavior. This intervention was tested with families (59% African American, 17% white, 24% mixed) recruited from medical practices serving Medicaid-insured patients who had at least one overweight or obese child (aged 4 to 12 years). The intervention was effective in preventing further weight gain with a trend toward decreased BMI (Cluss et al., 2010). Because parent BMI notification is a public health strategy that relies heavily upon effective communication, health literacy is of particular interest to evaluate the BMI letter. Thus, parent health literacy level should be investigated to determine its potential influence on conceptualization of children’s weight, understanding of the BMI letter, and decisions to change behavior in response to receipt of a BMI letter.
CHAPTER 5
HEALTH LITERACY

Definition of Health Literacy

Health literacy is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Ratzan and Parker, 2000). The “capacity” is a central component of health literacy, and any one individual’s capacity depends on education, culture, language, and health care settings (Nielsen-Bohlman, Panzer, & Kindig, 2004). This definition of health literacy has been modified slightly with the addition of “communicate” to the listed capacities in the text of the Patient Protection and Affordable Care Act H.R. 3590 (2010). In Title V of the law, health literacy is defined as “the degree to which an individual has the capacity to obtain, communicate, process, and understand health information and services in order to make appropriate health decisions.”

In defining literacy, it is important to distinguish the concept of health from general literacy. Literacy has been defined as “the ability to use printed and written information to function in society, to achieve one’s goals, and to develop one’s knowledge and potential” (White & Dillow, 2005, p. 4). Thus, literacy includes reading and comprehension of printed, spoken, and quantitative information, and using written documents required to perform various tasks in daily life, known as functional literacy (White & Dillow, 2005; Nielsen-Bohlman et al., 2004). This definition acknowledges that adults often read with a purpose in mind; literacy requires more than comprehension and decoding skills, which
involve using knowledge of letters and sounds to read words (Kutner, Greenberg, Jin, & Paulsen, 2006). The term “literacy” has also been used to describe knowledge of a specific subject area (Peerson & Saunders, 2009), such as “nutritional literacy” (Diamond, 2007). Although health literacy depends in part on literacy as described above, it is a separate concept pertaining to specific health-related capacities and contexts.

Questions of how best to define the multidimensional concept of health literacy continue to be debated. According to the description of health literacy proposed in the Institute of Medicine (IOM) report *Health Literacy: A Prescription to End Confusion*, health literacy requires individual capabilities in cultural and conceptual knowledge, speaking (oral) and listening (aural) skills, writing and reading skills (print literacy), and numeracy (Nielsen-Bohlman, Panzer, & Kindig, 2004). The inclusion of cultural and conceptual knowledge acknowledges that health literacy is context specific and an individual’s experiences with and understanding of health cannot be considered apart from one’s own culture. Aural literacy skills include navigating the use of technical and complex language, as well as pacing, density, and interactivity of dialogue (Roter, Erby, Larson, & Ellington, 2007). In instances of “dense” speech, the speaker talks for a relatively long period of time without interruption, which increases aural literacy demand. Conversely, interactive language refers to conversations with a rich back-and-forth exchange among participants, which reduces aural literacy demand (Roter et al., 2007). Speaking, or oral, literacy skills are less well studied than some other components of health literacy; namely, reading and writing skills.
(Koch-Weser, Rudd, & DeJong, 2010). However, many aspects of a typical patient-provider health care encounter require adequate oral and aural literacy skills for success (Rosenfeld et al., 2011), with some evidence suggesting high aural literacy skills may compensate for lower skills in another area, such as numeracy (Martin et al., 2011).

The final capability, numeracy, has been defined in health contexts to mean “the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions” (Golbeck et al., 2005, p. 375). Examples include proportions and percentages, life expectancy and risk, and blinding and randomization in research. Numeracy requires understanding and acting on concepts involving numbers that relate to health. Such tasks include determining the proper number of pills to take, analyzing whether lab values are within the normal range, or making treatment decisions based on probabilities of success and side effects (Golbeck et al., 2005).

In general, the relationship between print literacy and health outcomes has been the most highly studied component throughout the development of the field of health literacy. Many early studies assessed the relationship between print literacy skills and health outcomes such as hospitalization, medication adherence, depression, hypertension, and diabetes control (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Easton, Entwistle, & Williams, 2010) or the mismatch between readability levels of patient education materials and reading
levels of intended audiences (Dollahite, Thompson, & McKnew, 1996; Kicklighter & Stein, 1993). Thus, many health literacy measures emphasize print literacy skills. This relatively narrow emphasis has prompted a call from researchers for more comprehensive instruments, as well as more instruments that address other health literacy domains described above. The lack of comprehensiveness highlights the need to interpret research linking low health literacy levels to poorer health outcomes based on the components of health literacy measured during the course of any given study (Peerson & Saunders, 2009).

Prevalence of Limited Literacy and Limited Health Literacy

The field of health literacy research developed from the recognition that a significant proportion of patients were not being adequately served by the health care system (Nielsen-Bohlman, Panzer & Kindig, 2004). This recognition was informed by several national and international assessments that estimated the prevalence of limited literacy and later, limited health literacy.

The 1992 National Adult Literacy Survey (NALS) tested more than 26,000 Americans ages 16 years and older with a series of tasks to measure prose, document, and quantitative literacy skills and found that 21% to 23% of adults—which translates to 40 million to 44 million people—had skills in the lowest level of prose, document, and quantitative literacy (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993). Sixty-two percent of these individuals had not completed high school. Combined with individuals who had skills in the second-lowest level, the NALS found that 90 million Americans had limited literacy skills (Kirsch et al., 1993). In 2003, the follow-up National Assessment of Adult Literacy (NAAL) was
conducted among more than 19,000 Americans ages 16 years and older. Structured to facilitate comparison with the results of the NALS of 1992, the NAAL measured functional English literacy and reported separate scores for prose, document, and quantitative literacy. Literacy levels were reported as below basic, basic, intermediate, and proficient based on score ranges, which permitted comparison to scores from the 1992 assessment (Kutner et al., 2006). The NAAL found no significant changes in prose and document literacy of U.S. adults between 1992 and 2003; however, average quantitative literacy levels showed a significant increase from 275 to 283, on a scale of 0 to 500 (Kirsch et al., 1993).

In addition to measuring literacy levels, the NAAL was the first nationwide assessment to measure health literacy levels of U.S. adults and was intended to produce baseline data against which to compare future research. Results were reported in terms of four performance levels that correspond with types of tasks individuals at each level could be expected to perform: below basic, basic, intermediate, and proficient (Kutner et al., 2006). Individuals with below basic skills were likely to be able to identify drinks they could have based on written guidelines about preparing for a medical test. At the basic level, individuals who read a pamphlet about a specific disease could be expected to give two reasons a person without symptoms should be tested for that disease. More than one-third of participants scored in this range, with 22% basic and 14% below basic. At the intermediate level, individuals would be likely to use a graph of height, weight, and BMI to figure out a healthy weight range for a fictional person. This
group was the largest in the survey, with 53% of adults scoring in the intermediate health literacy range. Those with proficient health literacy (12%) could likely search through a document described as “complex” to define a medical term (Kutner et al., 2006). The large proportion of participants scoring in the two lowest levels represents a significant public health concern (Kutner et al., 2006).

In 2003, the Adult Literacy and Lifeskills Survey (ALL) put findings about literacy of U.S. adults in an international context. Six countries (Bermuda, Canada, Italy, Norway, Switzerland, and the United States) measured the literacy and numeracy skills of a representative group of 16- to 65-year-old individuals. The ALL was a successor to the International Adult Literacy Survey (IALS), which measured the prose, document, and quantitative literacy skills of individuals in 20 countries over three phases in 1994, 1996, and 1998. The IALS also demonstrated that a link between literacy and a country’s economic potential was plausible (Statistics Canada, 2004). In the ALL, prose, document, and quantitative literacy scores were reported from 0-500. Average U.S. scores in these areas were higher than those of Italy, but lower than those of all other participating countries (Lemke, Miller, & Johnston, 2005).

**History of Health Literacy as a Field of Study**

Findings of the NALS, NAAL, IALS, and ALL provided information about the scope of limited health literacy in the U.S. and the individuals whom it might be affecting. It set the stage for further health literacy inquiry and intervention. Early research in the 1990s made use of readability assessment formulas to
explore the mismatch between the readability levels of many health-related materials and the average reading levels of their intended audiences. Later research investigated three additional themes: health outcomes of patients with high versus low literacy skills, testing of strategies for improved health communication, and the development and evaluation of programs intended to improve health literacy (Rudd, Anderson, Oppenheimer, & Nath, 2007). As the field progressed, improving health literacy reached state and national legislative agendas. *Healthy People 2010* (U.S. Department of Health and Human Services [USDHHS], 2001) and later, *Healthy People 2020* (USDHHS, 2011) included a provisional health literacy objective. Mentions of health literacy (Somers & Mahadevan, 2010) in the Patient Protection and Affordable Care Act H.R. 3590 (2010), the passage of the Plain Writing Act H.R. 946 (2010), and the release of the National Health Literacy Action Plan (USDHHS, 2010) also reflect national attention devoted to health literacy. Current areas of research include the development of more comprehensive health literacy measures (including skills such as oral literacy) for individuals and populations, the expansion of health literacy interventions into community settings, the development of theory-based interventions in areas such as chronic disease, and the rigorous evaluation of health literacy interventions (Berkman et al., 2011; USDHHS, 2010).

**Factors Associated with Limited Health Literacy**

Data from the 2003 NAAL revealed that limited health literacy is associated with male gender, nonwhite race/ethnicity, limited use of the English language, older age (>65), lower levels of education, and lower socioeconomic
status (Kutner et al., 2006). In general, individuals with inadequate health literacy skills report lower disease knowledge, poorer health status, less frequent use of preventive services, and higher rates of hospitalization than individuals with marginal or adequate health literacy (Nielsen-Bohlman et al., 2004). These outcomes may be explained by evidence that health literacy influences whether patients obtain high-quality medical services and select a qualified healthcare provider (Vernon, Trujillo, Rosenbaum, & DeBuono, 2011). These factors all contribute to increased medical costs, with low health literacy estimated to cost the U.S. economy between $106 billion and $238 billion each year (Vernon et al., 2011).

**Measurement of Health Literacy**

The development of validated tools to assess individual health literacy levels in clinical and research settings has been central to advancing the field. Numerous health literacy assessments have already been reported in the literature, including general health literacy measures (Baker, Williams, Parker, Gazmararian, & Nurss, 1999; Davis et al., 1991; Weiss et al., 2005) and measures specific to particular diseases and health fields, such as cancer, nutrition, and diabetes (Agre, Stieglitz, & Milstein, 2006; Diamond, 2007; Ishikawa, Takeuchi, & Yano, 2008; Nath, Sylvester, Yasek, & Gunel, 2001) that directly test patient health literacy competencies, as well as brief sets of screening questions (Chew, Bradley, & Boyko, 2004; Jeppesen, Coyle, & Miser, 2009; Morris, MacLean, Chew, & Littenberg, 2006; Wallace, Rogers, Roskos, Holiday, & Weiss, 2006). Initially, some health literacy measures were validated
by comparing them to achievement tests that measure reading and/or math skills, such as the Slosson Oral Reading Test (SORT), the Peabody Individual Achievement Test (PIAT), and the Wide Range Achievement Test (WRAT). Some measures noted in Table 1 have been adapted to short forms for use in clinical environments, as well as use in languages other than English. However, significant limitations exist for many of these assessments, including problems of content validity, generalizability, and the absence of a single comprehensive health literacy measure (Baker, 2006; Jordan, Osborne, & Buchbinder, 2010; Pleasant & McKinney, 2011). A review of these measures, as well as their limitations, provides context for examining the body of research linking health literacy and nutrition-related health behaviors and outcomes.

Many health literacy measures rely on testing an individual's pronunciation and word recognition skills using lists of medical words that increase in difficulty, with little or no emphasis on comprehension. These measures include the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1991), the Short Assessment of Health Literacy in Spanish and English (SAHL—S&E) (Lee, Stucky, Lee, Rozier, & Bender, 2010), the Medical Term Recognition Test (METER) (Rawson et al., 2010), and the Medical Terminology Achievement Reading Test (MART) (Hanson-Divers, 1997). Of these, the REALM is oldest and most widely used. In its original form, the REALM contained 125 words related to medical care listed in ascending order of difficulty and scored according to grade levels. A patient is asked to read these words aloud until no more words can be pronounced correctly, which takes about three to five minutes (Davis et al.,
1991). A shortened REALM (Davis et al., 1993) and a brief revised version (REALM-R) (Bass, Wilson, & Griffith, 2003) with fewer words than the original test have been validated. However, the REALM does not measure comprehension or numeracy. It could not be adapted for Spanish speakers because written letters and their spoken sounds correspond closely in the Spanish language, making it too easy to pronounce unfamiliar words (Nurss, Baker, Davis, Parker, & Williams, 1995).

The Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA), the precursor to the Short Assessment of Health Literacy in Spanish and English (SAHL—S&E) (Lee et al., 2010), was developed specifically for Spanish speakers (Lee, Bender, Ruiz, & Cho, 2006). The SAHLSA is based on the REALM but includes a comprehension component, consisting of 50 words on flash cards that contain a REALM medical term and two association words—a key word with a similar meaning and an unrelated distractor word. For example, the medical term potasio (potassium) is accompanied by the key word mineral (mineral) and the distractor word proteína (protein). The test-taker is instructed to choose one of the two association words to demonstrate comprehension. However, subjects must be clearly instructed not to guess answers if they do not know them (Lee et al., 2006). Later development of the SAHL—S&E provided a comparable test of health literacy in Spanish- and English-speaking populations, but was not tested in a community-based sample and remained limited to testing of an individual’s reading skills (Lee et al., 2010).
Parker and colleagues developed a two-part health literacy test that went beyond assessment of reading ability to measure a patient’s ability to perform health-related tasks (Parker, Baker, Williams, & Nurss, 1995). Used extensively in research settings to date—and considered the “gold standard” of health literacy testing (Mancuso, 2009)—the Test of Functional Health Literacy in Adults (TOFHLA) measures health-related numeracy in addition to reading and comprehension in English or Spanish (Parker et al., 1995). The first portion asks individuals to answer questions that test understanding of information in medical scenarios, such as instructions on a prescription label or instructions about preparing for a medical procedure. The second portion is based on the cloze method, which consists of sentences of text with deleted words that must be replaced to demonstrate comprehension. In this second portion, individuals must select appropriate words from a multiple-choice listing to complete sentences about medical topics. Although the TOFHLA covers a wider range of health literacy competencies than many other assessments, utility of this timed tool is limited by its length (22 minutes), which can be burdensome for test-takers (Mancuso, 2009; Parker et al., 2005). Brief and short versions of the TOFHLA, both abbreviated in the literature as the S-TOFHLA (Mancuso, 2009), have been developed; however, comparison of the brief TOFHLA to the REALM demonstrates limitations regarding its reliability (Cronbach’s α=0.68) and validity (r=0.61) for the numeracy section, and the short TOFHLA only measures literacy (Baker, Williams, Parker, Gazmararian, & Nurss, 1999).
Two measures are more directly applicable to nutrition. In 2005, Weiss and colleagues developed a short health literacy instrument intended for clinical and research settings that measures reading, reasoning, and numeracy in English- and Spanish-speaking adults. The Newest Vital Sign (NVS) consists of a nutrition label accompanied by six questions, with fewer than two correct answers indicating a greater than 50% chance of having marginal or inadequate literacy skills (Weiss et al., 2005). A number of studies have demonstrated that the NVS can be administered quickly, usually in fewer than three minutes, and fewer than three percent of subjects decline to take the test (Johnson & Weiss, 2008; Weiss et al., 2005; Shah, West, Bremmeyr, & Savoy-Moore, 2010). However, a major limitation is its poor correlation with the TOFHLA (Mancuso, 2009). To date, the only measure designed to address “nutritional literacy” specifically is the Nutritional Literacy Scale (NLS), an untimed reading comprehension test that asks individuals to complete declarative statements about nutrition using a modified cloze procedure (Diamond, 2007). For example, the statement *Whole grains provide more ______ than processed grains* is accompanied by the multiple-choice options *weight, good, fiber,* and *nutritious.* The NLS was originally developed for application to metabolic syndrome and is the only instrument in the field that focuses on understanding of nutrition-related content. However, it has not be utilized extensively in research to date, and is not available in Spanish (Diamond, 2007).
Limitations of Health Literacy Measurements

The measures included in Table 1 represent those that are most commonly used and are relevant to the field of nutrition. When selecting measures and interpreting their results, significant limitations must be considered, including the absence of a comprehensive tool, the lack of consensus regarding the definition of health literacy and its underlying conceptual framework, and issues of face validity, cultural sensitivity, generalizability, and responsiveness (Baker, 2006; Jordan, Osborne, & Buchbinder, 2010; Pleasant & McKinney, 2011).

Because no measure is comprehensive, Pleasant proposed that currently available health literacy instruments may be more accurately described as “screeners” than measures (2009). In clinical medicine, a screener indicates whether a person is “sick” or “not sick.” Conversely, a measure is “an attempt to explore in-depth the structure and function of objects of interest” (Pleasant, 2009, p. 18). It would be ideal to base the development of a screening tool on a true measure of health literacy, which would assess not only patient abilities, but also patient-provider interactions in the context of the health care system (Pleasant, 2009) and cultural knowledge. However, Baker cautions against assuming that increased comprehensiveness will improve the predictive value of health literacy measures (2006).

As the field of health literacy has expanded, the term “health literacy” has been defined and understood differently by various audiences (Baker, 2006). The resulting lack of consensus about a definition of health literacy and its domains
may preclude the development of a comprehensive measurement tool (Frisch, Camerini, Divani, & Schulz, 2011; Mancuso, 2009). Stakeholders differ on questions of whether health literacy is limited to individual-level factors or the broader context of the health care system (Baker, 2006); whether health literacy should be conceptualized as an asset for health promotion or a risk to be managed (Nutbeam, 2008; Zarcadoolas, Pleasant, & Greer, 2005); and whether the scope of health literacy is defined by the clinical or public health environment (Freedman et al., 2009).

Defining health literacy by the capabilities outlined in the Institute of Medicine report places significant emphasis on an individual’s health literacy level and skills (Nielsen-Bohlman et al., 2004). However, such a definition may ignore that fact that health literacy, being described as the ability to function in a health care environment, is a “dynamic state” and depends on characteristics of the health care system that are not measured with validated assessment tools (Baker, 2006). In addition, some believe health literacy should be limited to the exercise of specific capacities in a defined health care setting (Davis et al., 1991; Parker et al., 1995), while others take a broader view (Peerson & Saunders, 2009). According to the latter approach, health literacy relates to making any health-related decisions in any setting and encompasses everyday choices that affect general wellness (Peerson & Saunders, 2009), such as deciding which foods to purchase from a grocery store.

Some researchers propose that an ethical imperative exists to broaden the scope of inquiry related to health literacy (Gazmararian, Curran, Parker,
Bernhardt, & DeBuono, 2005). In a move beyond the primarily individual-level construct, Freedman and colleagues (2009) introduced the concept of “public health literacy,” which integrates social and systemic factors affecting health. Public health literacy is defined as “the degree to which individuals and groups can obtain, process, understand, evaluate, and act on information needed to make public health decisions that benefit the community” (Freedman et al., 2009, p. 448).

Perhaps due to this lack of consensus in defining the concept, the REALM (Davis et al., 1991), SAHLSA (Lee et al., 2006), NVS (Weiss et al., 2005), and MART (Hanson-Divers, 1997) do not clearly state an underlying conceptual framework or state the construct(s) intended for measurement (Jordan et al., 2011). In addition, Jordan and colleagues have questioned the face validity of the instruments because scoring schemes differ from one measure to another; the TOFHLA’s three scoring categories have been characterized as poorly defined, and it is unclear whether the NVS classifications overlap (2011). Because such variation is present across measurement approaches and scoring methodologies, results cannot be easily compared across studies to firmly establish the relation of health literacy to health status (Pleasant & McKinney, 2011). Future research on health literacy measures is needed to refine scoring categories, obtain reliability and responsiveness data from randomized controlled trials, develop more comprehensive instruments, and articulate the conceptual framework being measured (Jordan et al., 2011). These conceptual inconsistencies and previously discussed psychometric limitations of current
health literacy measures must be considered when interpreting studies of health literacy and nutrition and when proposing methodologies for such studies.

Measurement of Readability

Related to health literacy is readability, which refers to the predicted difficulty of reading printed material based on its vocabulary, word length, and sentence length (Friedman & Hoffman-Goetz, 2006). Recognition that patient education materials with readability levels often reaching ninth grade or higher did not match the reading skills of many users (Dollahite, Thompson, & McNew, 1996; Hill-Briggs & Smith, 2008; Kicklighter & Stein, 1993) provided an impetus for health literacy research when the field was in its infancy. More than 40 formulas now exist to calculate readability levels of printed materials as depicted by their estimated reading grade level (Doak, Doak, & Root, 1996). Some of the most commonly used formulas and their components are described in Table 2. These formulas include the Flesch Reading Ease Scale (Flesch, 1948), Flesch-Kincaid Reading Grade Level (Kincaid, Fishburne, Rogers, & Chissom, 1975), Simplified Measure of Gobbledygook (SMOG) (McLaughlin, 1969), Gunning Frequency of Gobbledygook (FOG) (Gunning, 1952), and the Fry Readability Graph (Fry, 1968). Many readability formulas produce similar but not identical results. For example, the correlation coefficient between Fry and Flesh Reading Ease levels in one study was -0.97 (Dollahite et al., 1996). Conversely, the Flesch-Kincaid formula may underestimate the reading level of written materials by approximately two grades (Burke & Greenberg, 2010).
These readability formulas are useful to provide a rough assessment of a printed material’s appropriateness for the reading skills of an intended audience, with a maximum of a sixth-grade level being suited to most uses in health care (Doak et al., 1996). However, some research suggests a fourth- to eighth-grade level is an acceptable range (National Institutes of Health [NIH] Plain Language Initiative, 2002). A major drawback of readability formulas is their inability to assess additional characteristics of written documents known to affect ease of use, such as grammar and syntax, background knowledge, cultural context, coherence, print size, type style, color contrast, and density of information (Bailin & Grafstein, 2001; Doak et al., 1996). Another method that assesses some of these characteristics in printed documents is the Suitability Assessment of Materials (SAM), which can provide useful information about a material’s appropriateness for a given population and goes beyond reading level (Doak et al., 1996). The SAM evaluates 22 factors, which fall within the categories of content, literacy demand, graphics, layout, typography, learning stimulation, motivation, and cultural appropriateness. It yields a percentage score that denotes whether the material is considered superior, adequate, or not suitable and suggests areas where revision is needed (Doak et al., 1996).

**Health Literacy and Nutrition**

**Health Literacy and Chronic Disease Management**

The term “nutrition literacy” has been defined as “the degree to which individuals have the capacity to obtain, process, and understand basic nutrition information and services needed to make appropriate dietary decisions”
Investigation of health literacy in the context of nutrition is relatively new. The body of research linking health literacy to disease knowledge (Gazmararian, Williams, Peel, & Baker, 2003) and health outcomes in nutrition-related chronic diseases, such as cardiovascular disease (Safeer, Cooke, & Keenan, 2006), renal disease (Cavanaugh et al., 2010; Devraj & Gordon, 2009) and diabetes mellitus (Schillinger et al., 2002), demonstrates its importance and provides context for interpreting emerging findings in nutrition. Diabetes, particularly type 2, has been an active area of health literacy research regarding patient outcomes, knowledge, self-management behaviors, and response to health literacy-adapted interventions.

Health Literacy and Diabetes Outcomes

Among individuals with type 1 and type 2 diabetes, low health literacy is associated with poorer disease knowledge (Gazmararian et al., 1999; Gazmararian et al., 2003; Schillinger et al., 2002; Williams, Baker, Parker, & Nurss, 1998), poorer glycemic control and more self-reported diabetes complications (Gazmararian et al., 1999; Kim, Love, Quistberg, & Shea, 2004; Schillinger et al., 2002), and more frequent significant episodes of hypoglycemia (Sarkar et al., 2010). However, these findings are cross-sectional and factors underlying the associations remain unclear.

Factors Connecting Low Health Literacy and Diabetes Outcomes

One hypothesized contributor to the association between low health literacy and diabetes outcomes is differences in self-management behaviors among patients (Kim et al., 2004). In a prospective observational study of
predominantly Black, English-speaking adults enrolled in diabetes education classes at an urban teaching hospital, 92 individuals completed the S-TOFHLA (reading comprehension section) and the Summary of Diabetes Self-Care Activities Measure (SDSCA), which assesses weekly frequency of diabetes self-care activities (diet, exercise, self-glucose monitoring, foot care, and medication adherence) (Toobert, Hampson, Glasgow, 2000). At 3 month follow up, patients with adequate health literacy had higher knowledge scores (P<.000) and exercised more (P<.022), but those with lower literacy had better reported adherence to diet (P<.000), self glucose monitoring (P<.002), and foot care (P<.001). More patients in the limited literacy group had previously received diabetes education, although the difference was not significant (28.6 vs. 17.6%, P=0.276), which the authors suggested may have contributed to the unexpected differences between patients with adequate and limited literacy. Because only the S-TOFHLA reading comprehension section was used to measure health literacy levels, further study is warranted with a measure that assesses numeracy because of the importance of numerical reasoning for self-management activities, such as blood glucose control.

Numeracy skills in particular have also been explored as a potential contributor to the observed association between low health literacy and diabetes outcomes. A cross-sectional analysis of 383 adults with type 2 diabetes at primary care and diabetes clinics found that diabetes-related numeracy was a strong predictor of hemoglobin A1c (r=-0.46, P<.001) and reduced the previously observed association (r=0.12, P<.01) between African American race
and poor glycemic control to nonsignificance (r=.10, NS) (Osborn, Cavanaugh, Wallston, White, & Rothman, 2009). Interestingly, another cross-sectional survey of 398 adult type 1 and type 2 diabetes patients (63% white, 51% female) enrolled from three medical centers found that diabetes-related numeracy scores (as assessed by the Diabetes Numeracy Test [DNT]) were only modestly associated with hemoglobin A1c level after adjustment for potential confounders (Cavanaugh et al., 2008). Among adults in this study with low health literacy (<ninth-grade level per the REALM), median A1c was 7.6% in the lowest quartile of DNT scores (IQR, 6.7-9.3) and was 6.3% in the highest quartile of DNT scores (IQR, 5.5-8.1) (P=.014) (Cavanaugh et al., 2008). More current research suggests diabetes self-efficacy may be more directly related to glycemic control than health literacy or numeracy (Osborn, Cavanaugh, Wallston, & Rothman, 2010).

**Poor Readability of Traditional Diabetes Diet Education Materials**

Another factor that may contribute to poorer outcomes among diabetics with low health literacy skills is educational materials that have not been meeting their learning needs. Four studies have demonstrated that the majority of printed diet and health patient education materials in general (Dollahite et al., 1996) and diabetes nutrition education materials in particular (Hill-Briggs & Smith, 2008; Joram et al., 2011; Kicklighter & Stein, 1993) are written at a readability level—often at or above ninth grade—that is too high for individuals with limited literacy and numeracy skills.
Kicklighter & Stein (1993) assessed the readability and comprehensibility of a previous version of the *Exchange Lists for Meal Planning*, published by the American Diabetes Association and the American Dietetic Association. Among 58 predominantly white individuals with diabetes (aged 15 to 74 years) recruited from outpatient education programs, comprehension of the printed diet material was assessed using the cloze technique. In addition, readability level was assessed using the Flesch-Kincaid, Flesh Reading Ease, and Gunning Fog Index formulas, with grade level results of 7.5, 8-9, and 10.9, respectively. Among cloze scores, 62% were below 40%, which indicates the material was too difficult to comprehend. An additional 21% were between 40% and 59%, which suggests the need for supplemental instruction. Only 17% of participants achieved a score that indicated they could fully comprehend the material, despite a mean years of schooling of 14 in the study population. Because of these low scores, the authors concluded that current diet education materials were not meeting the educational needs of many patients with diabetes.

A study conducted 15 years later by Hill-Briggs & Smith (2008) came to similar conclusions. The readability and suitability of 40 diabetes or cardiovascular disease (CVD) printed patient education materials from the American Diabetes Association and the American Heart Association were evaluated for appropriateness in limited literacy populations based on literacy demand and behavioral activation but not actual patient comprehension. Literacy demand refers to the ease with which individuals can read, process, and comprehend material, and behavioral activation deals with the usefulness of
information to individuals—that is, whether nutrition and physical activity recommendations can be easily applied to their lives. Only 6 of 23 literacy demand criteria and 2 of 9 behavioral activation criteria were met across the sample, with many materials failing to meet recommended readability levels, use font sizes that are easy to read, and limit technical terms and excess information (unmet literacy demand criteria). Additionally, many materials failed to devote more than half of content to recommended behaviors, provide set-by-step instructions, and keep information and suggestions relevant to low literacy audiences (unmet behavioral activation criteria). Thus, development and testing of appropriate materials was identified as an area of need in health literacy and diabetes research.

**Efficacy of Literacy- and Numeracy-Adapted Education Materials**

Based on needs identified in the previous study, Hill-Briggs and colleagues (2008) developed and pilot tested low-literacy adapted (<fourth grade reading level) diabetes and CVD education materials modified to meet literacy demand and behavioral activation criteria. Thirty African American volunteers at high CVD risk and with below average (n=15) and average (n=15) literacy skills were recruited from an urban managed care organization and asked to complete a pre- and post-test survey. Although a significant increase in knowledge was observed among groups with below average and average literacy skills following education with the materials and a class, behavior change outcomes were not measured and the sample size was small, which are significant limitations of the study. However, in another study of modified diabetes education materials,
behavior change was assessed. Wallace and colleagues (2009) measured changes in knowledge, self-efficacy, and self-reported behaviors in a pilot study of a low literacy diabetes education guide (*Living with Diabetes*) used with brief counseling sessions in a primary care setting with 250 predominantly low literacy, English- and Spanish-speaking type 2 diabetes patients. Significant improvements (P<.001) at post-test were observed in diabetes self-efficacy and self-care activities (including maintaining a recommended diet) as measured by validated scales (Wallace et al., 2009). Both of these pilot studies did not compare patients to a control group.

Three randomized controlled trials have added to the evidence suggesting health literacy-adapted interventions may be more effective than traditional care in improving diabetes outcomes in the short-term among persons with low health literacy. In one trial by Rothman and colleagues (2004), 193 socioeconomically diverse patients with poorly controlled diabetes (HbA1c levels >8%) were referred by their primary care providers and randomized to intervention or control groups. For one year, control patients received usual care from their primary care provider and intervention patients received supplemental intensive diabetes management with one-to-one education, medication management, and strategies to address barriers to care delivered by health care providers. Health care providers individualized communication to patients in the intervention group, based on their literacy status as measured by the REALM. For patients with low literacy, techniques to enhance comprehension such as verbal education, picture-based materials, and “teach back” methods were used. “Teach back”
refers to the practice of asking patients to repeat key points or instructions in their own words, which allows providers to check for understanding. In this study, intervention patients with low literacy were more likely than controls to achieve goal HbA1c levels ($\leq 7\%$) at follow up (42% vs. 15%, respectively; adjusted OR, 4.6, 95% CI: 1.3, 17.2). However, the measurement tool (REALM) and intervention components described addressed issues of health literacy in general rather than numeracy, which has been demonstrated to be important in diabetes management as discussed previously.

In an intervention adapted for both low literacy and numeracy skills, Wolff and colleagues (2009) developed the Diabetes Literacy and Numeracy Education Toolkit (DLNET) to facilitate education and self-management in patients with low literacy and numeracy skills. The DLNET included 24 interactive modules with color coding, illustrations, and a fourth- to sixth-grade reading level (Wolff et al., 2009). Two coordinated randomized controlled trials assessed the effect of providing three months of enhanced diabetes care using the DLNET from providers specially trained in health communication, as compared to usual care, among 198 adults (43% African American) with predominantly limited literacy and numeracy skills (Cavanaugh et al., 2009). Outcomes were also measured at 6 month follow-up (3 months after program completion). Although greater improvement was seen in hemoglobin A1c in the intervention group than the control group at three months ($P=0.03$), no significant difference remained at 6 months' follow up. In addition, no significant differences were found in self-management behaviors between the two groups. The lack of difference may be
explained by the high level of care already provided by the “usual care” control group, or the DLNET may function better for ongoing disease management than for short-term self-management training among individuals with low health literacy (Cavanaugh et al., 2009). Clearly, more study is needed to explain the inconsistent outcomes of diabetes interventions adapted for limited health literacy populations.

In summary, existing literature highlights the potential role of health literacy in a number of nutrition-related chronic diseases. In particular, literacy and numeracy have been shown to influence glycemic control in diabetes. More research is warranted to clarify the factors underlying this relationship. Available data suggests that many currently used general nutrition and diabetes diet education materials do not meet the needs of individuals with low health literacy. Further randomized controlled trials to test the efficacy of theory-based, low-health-literacy adapted interventions will be critical to advancing the field as well.

**Health Literacy, Weight Management, and Dietary Behaviors**

The body of research linking health literacy directly to nutrition is limited and has some mixed results. One area in which health literacy in general—and numeracy in particular—has been demonstrated to influence nutrition is in cross-sectional studies of weight management and related behaviors. Numeracy skills (as measured by the WRAT-3) were significantly negatively correlated with BMI (rho= -0.26, P=.001) in a cross-sectional convenience sample of 160 English-speaking adults (mean 46 years, 70% female, 55% non-white) recruited from a primary care clinic. However, literacy skills (as measured by the REALM) were
not associated with BMI (Huizinga, Beech, Cavanaugh, Elasy, & Rothman, 2008). This correlation remained significant after adjustment for age, sex, race, income, years of education, and literacy (beta coefficient= -.14, P=.010). In contrast, a study of 2,923 Medicare managed-care enrollees in four U. S. metropolitan areas did not find an association between health literacy level as measured by the S-TOFHLA (consisting of both its literacy and numeracy sections) and overweight or obesity (Wolf, Gazmararian, & Baker, 2007). The cross-sectional nature of these studies makes it difficult to draw definitive conclusions about any relationship between BMI and health literacy or numeracy.

Few studies provide insight into the skills that may contribute to the observed association between health literacy and increased BMI. The skills studied include awareness of food intake, portion-size estimation, and food label interpretation. A study of a convenience sample of 35 low-income women (19 to 46 years old) designed to test the accuracy of the multiple-pass 24-hour dietary recall used doubly labeled water to measure energy expenditure. Literacy (but not health literacy) measured by the WRAT and body fatness measured by dual energy x-ray absorptiometry (DXA) predicted misreporting of energy intake (r=.52, P=.006) (Johnson, Soultanakis, & Matthews, 1998). Although limited by a small convenience sample, these findings suggest that low-literate, overweight individuals may have poorer awareness of their food intake, which could hamper weight loss efforts.

Additional behaviors related to dietary self-monitoring have also been linked to health literacy. A cross-sectional convenience sample of 164
predominantly white and female primary care patients investigated the relationship between literacy and the ability to estimate a standard food portion (Huizinga et al., 2009). Literacy (as measured by the REALM), but not numeracy (as measured by the WRAT-3) was associated with inaccurate portion size estimation when participants were asked to serve a single serving (OR: 2.54, 95% CI: 1.11, 5.81) (Huizinga et al., 2009). Inaccurate portion size estimation was defined as serving a portion not within 25% of the standard size. These data suggest that poorer portion size estimation skills among individuals with limited health literacy may contribute to misreporting of energy intake and again, make losing weight more difficult. A related factor influencing weight loss efforts, food label reading skills, was investigated in another convenience sample of 200 primary care patients (72% female, 67% white). This study used a Nutrition Label Survey assessed for reliability (KR-20=0.87) to measure patient comprehension of food labels. Higher comprehension was significantly correlated (P<.001) with literacy (as measured by the REALM [rho=0.52]) and numeracy (as measured by the WRAT-3 [rho=0.67]) (Rothman et al., 2006). Thus, individuals with low health literacy and/or numeracy skills in this study may have had greater difficulty recalling their food intake, serving themselves appropriate portion sizes, and interpreting food labels to make dietary decisions.

Although limited, this collection of findings suggests that individuals with low health literacy skills may make food selection decisions that adversely impact their nutrient intake and energy balance. Recently, this idea been explored in more detail. A cross-sectional study of 400 predominantly African American, low-
income adults (22% overweight, 52% obese) in the rural lower Mississippi Delta used a validated regional food frequency questionnaire (FFQ) and subsequent calculation of Healthy Eating Index-2005 (HEI) scores from FFQ data, as well as the Newest Vital Sign (NVS) health literacy measure (Zoellner et al., 2011). Multiple linear regression was used to regress health literacy scores, education level, age, race, sex, income level, and SNAP participation on HEI-2005 scores and sugar-sweetened beverage (SSB) intake for 376 participants.

The study found an important association between health literacy skills and dietary quality, with individuals in the lowest category of health literacy skills scoring significantly lower on the HEI-2005 and consuming significantly more calories per day from SSBs. Participants with adequate health literacy skills scored approximately four points higher on the HEI than those with a high likelihood of or possibility of limited health literacy (P<0.01). In addition, individuals in the lowest health literacy category consumed about 119 more calories per day from SSBs than those with adequate health literacy (P<0.01). While controlling for all other variables, the multivariate linear regression model showed a one-point increase in health literacy scores was associated with a 1.21-point increase in HEI scores (P<0.01) and with 34 fewer kilocalories per day from SSBs (P=0.01). Notably, health literacy was the variable showing the strongest association with HEI scores and SSB consumption, whereas income and education level variables were not significant (Zoellner et al., 2011). Findings from this study led authors to suggest that inconsistent findings regarding the association of HEI scores with demographic and socioeconomic variables
previously reported in the literature might be explained by differences in health literacy among study participants (Zoellner et al., 2011).

**Future Research Needs in Nutrition and Health Literacy**

Some research has assessed how health literacy is associated with nutrition-information gathering. In a previous study of 177 adults in the lower Mississippi Delta region, nearly one-quarter (24%) demonstrated a high likelihood of low health literacy skills as measured by the NVS. On average, these individuals also reported limited use of and trust in the Internet to obtain health information; instead, they preferred television or a health care provider as their source of information (Zoellner, Connell, Bounds, & Crook, 2009). Because they displayed low levels of knowledge about the Dietary Guidelines for Americans (U. S. Department of Agriculture [USDA] & USDHHS, 2010) and only 12% correctly identified the MyPyramid graphic (USDA, 2005), the authors concluded the use of technology was problematic for reaching impoverished populations with low health literacy (Zoellner et al., 2009). Other research with low-health-literate audiences has also suggested that some individuals avoid .gov websites due to perceived complexity or lack of trust in governmental information (Mackert, Kahlor, Tyler, & Gustafson, 2009). These findings should be considered in the design of future health literacy interventions in nutrition.

Because nutrition is an emerging area of inquiry in health literacy, a variety of future research needs merit discussion. More work is needed to identify how literacy and numeracy may be associated with specific food- and nutrition-related behaviors, and to identify the factors responsible for observed
associations. In its report on front-of-package nutrition rating systems and symbols, the Institute of Medicine called for additional research on the implications of low health literacy for nutrition labeling (Wartella, Lichtenstein, & Boon, 2010). Collectively, such studies can inform the development of theory-based nutrition education and behavior change interventions—particularly with respect to obesity prevention and management—that are tailored for audiences with low health literacy and tested for efficacy in experimental studies. A recent systematic review of nutrition and health literacy identified additional areas of future research needs, including the examination of long-term effects of health literacy interventions on nutrition outcomes (Carbone & Zoellner, 2012). In addition, another recent systematic review of health literacy interventions for health promotion identified 24 clinic-based studies and only one community-based study, indicating the need for greater community-based research to reach populations with low health literacy skills (Allen, Zoellner, Motley, & Estabrooks, 2011).

From a broader perspective, future research on health literacy and nutrition can also address the emerging concept of public health literacy, which is designed to address the social determinants of health literacy in populations and engage the public in promoting health. Investigators have called for the development of interventions that improve public health literacy and use it to promote actions that improve public health problems (Freedman et al., 2009). In the field of nutrition, a potential application of public health literacy may lie in addressing the need to reframe obesity discourse focused on "individual
responsibility” solutions and refocus this discourse on environmental causes of obesity (Dorfman & Wallack, 2007). A public health literate society may be more adequately equipped to recognize the opportunities for furthering primary prevention strategies in combating obesity and addressing its social, environmental, and economic determinants. The emerging concept of public health literacy therefore warrants additional attention in the field of nutrition research.

The current body of literature linking nutrition and health literacy is limited. A majority of studies on health literacy, weight management, and dietary behaviors are cross-sectional and do not assess how changes in health literacy affect nutrition over time. Because these cross-sectional studies can only examine associations between nutrition-related behaviors and low health literacy skills, qualitative insight is needed to understand how and why health literacy influences nutrition. In addition, although health literacy has been investigated with respect to weight management, parents’ health literacy has not been examined in relation to childhood obesity. Again, this research gap can be addressed with qualitative studies to determine how the parents conceptualize children’s weight, their understanding of and reactions to the BMI letter, and the influence of varying levels of health literacy skills on these outcomes.

**Future Research Needs in Health Literacy and BMI Screening**

Questions of how best to define and measure health literacy continue to be debated, and no comprehensive measure exists. Many health literacy measures rely on testing an individual’s pronunciation and word recognition skills
using lists of medical words that increase in difficulty, with little or no emphasis on comprehension. The conceptual inconsistencies and psychometric limitations of current health literacy measures must be considered in study design and interpretation. Investigation of health literacy within the field of nutrition is relatively new, and the body of research linking health literacy directly to nutrition is limited. However, with some mixed results, health literacy has been demonstrated to influence body weight (Huizinga et al., 2008; Huizinga et al., 2009), portion size estimation (Rothman et al., 2006), and dietary quality (Zoellner et al., 2011). Further study is needed to identify how literacy and numeracy relate to specific nutrition-related behaviors. In addition, qualitative research is needed to understand how and why health literacy influences nutrition and to expand on existing cross-sectional studies. Although health literacy has been investigated with respect to weight management, parents’ health literacy skills have not been studied in the context of childhood obesity and relevant behaviors.

One important factor that has not been studied in relation to communicating with parents about their child’s BMI is health literacy. Low health literacy in adults negatively impacts understanding of preventive care information (Sanders, Shaw, Guez, Baur, & Rudd, 2009). Previous research in adults has also demonstrated a connection between low health literacy skills and poor weight management behaviors (Huizinga et al., 2009; Rothman et al., 2006; Zoellner et al., 2011), and a parent’s health literacy level has been shown to influence other child health outcomes, such as glycemic control in children with
type 1 diabetes (Hassan & Heptulla, 2010; Janisse et al., 2009). Further, some evidence suggests that attention to health literacy needs could improve the efficacy of interventions to reduce BMI (Cluss et al., 2010). Because parent BMI notification is a public health strategy that relies heavily upon effective communication, health literacy is of particular interest to evaluate the BMI letter. Thus, parent health literacy level should be investigated to determine its potential influence on conceptualization of children’s weight, understanding of the BMI letter, and decisions to change behavior in response to receipt of a BMI letter.
CHAPTER 6
PURPOSE OF THE CURRENT STUDY

In February 2009, in response to amendments made to the regulations on Physical Examination of School Children (105 CMR 200.000), Massachusetts began requiring measurement of height and weight and BMI/BMI percentile calculation for students in grades 1, 4, 7 and 10, followed by direct, confidential written notification to parents and provision of screening data to the state department of public health (MA DPH, 2009). Since 2010, all public schools in Massachusetts have been required to conduct BMI screening for students in these grade levels and to notify parents of the results in a written, direct, and confidential manner, which is typically a letter mailed home (MA DPH, 2010). In a recent online survey of 286 Massachusetts pediatricians (40% response rate), 16.1% strongly supported the program, whereas 12.2% strongly opposed it, with more positive attitudes among pediatricians in urban areas (P<.001) (Pietras, Rhodes, Meyers, & Goodman, 2012). Open-ended responses included concerns about children’s self-esteem, teasing, dieting, and eating disorders, as well as the lack of resources for treatment (Pietras et al., 2012). However, the BMI letter in Massachusetts has not been evaluated for its acceptability to parents, its effect on parents’ assessments and behaviors regarding their child’s weight, or its comprehensibility.

The recent introduction of the Massachusetts BMI letter, combined with identified gaps in the literature, presents a unique opportunity to conduct a
qualitative study of the ways in which parents conceptualize their children’s weight and react to the BMI letter, while exploring the potential influence of parent/caregiver health literacy on responses to and understanding of the BMI letter. Such research can inform an approach to respectfully and effectively communicate BMI results to parents in Massachusetts and nationwide.
CHAPTER 7
RESEARCH QUESTIONS, SPECIFIC AIMS, AND HYPOTHESES

For specific aims that will be addressed using only qualitative methods, hypotheses have not been developed. Each of the questions, aims, and hypotheses listed below will apply to parents of obese children in the Springfield, MA area.

RQ 1. What is the readability level of the Massachusetts (MA) BMI letter and educational materials sent home to parents/caregivers?

Specific Aim 1. To evaluate the readability of the MA BMI letter and educational materials.

Hypothesis 1. The MA BMI letter and educational materials are written at a reading level that is at or below sixth grade.

RQ 2. What is the health literacy level of selected parents/caregivers in Massachusetts who are part of the intended audience of the BMI letter?

Specific Aim 2a. To assess the health literacy levels of parents who are part of the intended audience of the BMI letter.

Hypothesis 2a. Parents will have a range of health literacy skills.

Specific Aim 2b. To test the feasibility of assessing health literacy levels of parents by using the Newest Vital Sign (NVS) in a group setting.

Hypothesis 2b. It is feasible to administer the Newest Vital Sign to parents in a group setting.

RQ 3. How can information about children’s weight be effectively and respectfully communicated to parents/caregivers?

Specific Aim 3a. To examine parents’ reactions to terms and phrases used in print and oral communication about their children’s weight.

Specific Aim 3b. To examine parents’ preferences for terms and phrases used for communicating about their children’s weight.
Specific Aim 3c. To identify (based on the findings of Specific Aims 1, 2, 3a, & 3b) terms and phrases that may be used to effectively and respectfully communicate with parents about their children’s weight.

RQ 4. How do selected parents/caregivers respond to the MA BMI letter?

Specific Aim 4a. To examine parents’ reactions to the MA BMI letter.

Specific Aim 4b. To examine parents’ understanding of the MA BMI letter.

Specific Aim 4c. To identify relevant actions parents plan to take/have taken as a result of receiving the MA BMI letter.

Specific Aim 4d. To identify ways the BMI letter could be made more effective and respectful.

Specific Aim 4e. To identify additional education information that could accompany the letter to support positive behavior change among parents and children.
CHAPTER 8

METHODS

Overview of Study Design

This research was a qualitative study of parents/caregivers of school-age children seeking treatment for weight management. These parents had a school-age (8- to 14-year-old) child referred by a pediatrician to a family-based, intensive weight management program based on having a BMI at or above the 95th percentile. First, informed consent was obtained from all participants. Demographic information was collected from parents with a survey. Eight audio-taped focus groups (each with two to six participants) totaling 29 parents/caregivers were conducted. A semi-structured focus group guide was used to conduct focus groups to elicit parents’ responses to weight-related language and the Massachusetts (MA) BMI letter. As a group, the focus group participants also completed a validated Newest Vital Sign health literacy assessment. Readability assessments of the MA BMI letter and educational materials sent home to parents were conducted separately using five commonly available readability formulas.

Study Population and Recruitment

The study population was drawn from a convenience sample of parents of children in the Baystate Pediatric Weight Management Program (BPWMP) and enrolled in the Moving, Improving, and Gaining Health at the YMCA (MIGHTY) program in Springfield, MA. Patients referred to the BPWMP range from 2-21 years in age (60% are 8 to 14 years) and must have a BMI > 95th percentile. Of
those who report their race/ethnicity, 43% are white, 38% are Hispanic, and 19% are Black or “other” (Goff, 2011). Patients and families served by the BPWMP may choose to participate in MIGHTY, which is an affiliated intensive, family-based weight management program at the Springfield YMCA. All parents selected to participate in this study had at least one child beginning the MIGHTY program. Whether they had other children who participated previously was not assessed. The MIGHTY program consists of three to four groups of 5 to 10 families with rolling admissions every two to three months, with a total of 155 families participating in 2009-2010 (Goff, 2011). Following an information session, groups meet for two hours every other week over the six-month period; the first hour is spent together with a dietitian or behavioral specialist, and parents and children work separately with an exercise specialist during the second hour.

MIGHTY program specialists distributed a one-page flier about the study (Appendix A) to parents at the information session. At the first group session in the program’s main group meeting room, recruitment was conducted by this author (Appendix B), and informed consent (Appendix C) was obtained by a Baystate research assistant using a standardized process. Recruitment was conducted at this time because only enrolled parents, who will be returning for future classes, are in attendance. To be eligible for this study, parents/caregivers had a child beginning participation in the MIGHTY program, spoke and understood English, and were available for a one-hour focus group held during regularly scheduled exercise time for MIGHTY. Parents were informed that focus
groups would only be conducted in English. During recruitment, all participants also completed a demographic survey (Appendix D) to provide information about their level of education, race/ethnicity, number of children and their ages, and the language spoken most often in their home. A description of the important points in the informed consent, as well as step-by-step directions for completing the informed consent and the demographic survey were explained by this author and a Baystate research assistant (Appendix B) to ensure understanding and provision of accurate information.

Next, participants were given a reminder sheet (Appendix E) with the date and time of their next MIGHTY group meeting, at which time the focus group was conducted during the exercise hour. (Because parents in MIGHTY were given a free six-month YMCA membership, they could “make up” their exercise at a later time if desired.) One day prior to each focus group, participants received a reminder phone call (Appendix F) or text message (Appendix G) using a standardized format, according to their stated preference on the demographic survey. If participants did not answer the phone, they were called a second time before a voicemail message was recorded. Because of limited attendance at the last two focus groups, individuals who did not attend were contacted and given the opportunity to participate in another focus group scheduled during their next MIGHTY class. This author contacted the individuals who did not attend by phone or text message according to their stated preference, using a standardized format.
Health Literacy and Readability Measures

Although no health literacy measure is comprehensive, many options are available (Table 1). For this study, selection of a health literacy assessment tool was based on its relevance to nutrition, ease of use in a group setting, length, and measurement of numeracy, which has been associated with weight management (Huizinga et al., 2008; Rothman et al., 2006). The Newest Vital Sign (NVS) (Weiss et al., 2005) was selected because it met these criteria and it measures reading, reasoning, and numeracy in English- and Spanish-speaking adults. Only the English version was used in this study. The NVS consists of a nutrition label accompanied by six questions. Fewer than two correct answers indicates a greater than 50% chance of having marginal or inadequate health literacy skills (Weiss et al., 2005). It has been validated with the S-TOFHLA (r=0.61) and the full TOFHLA (r=0.59) and has a Cronbach’s α=0.76 (Osborn et al., 2007; Weiss et al., 2005). The relatively low correlation with the TOFHLA may reflect the high sensitivity of the NVS to marginal health literacy (Weiss et al., 2005). A number of studies have demonstrated that the NVS can be administered quickly, usually in less than three minutes, and fewer than three percent of subjects decline to take the test because of acceptability (Johnson & Weiss, 2008; Shah, West, Bremmeyr, & Savoy-Moore, 2010; Weiss et al., 2005). In the study by Shah and colleagues, which recorded the number of participants who declined to take the NVS, the adult participants (n=808) were similar to the MIGHTY parents/caregivers in age and educational level. The mean age was 44.9 years (compared to 40.6 years in the present study) and the proportion of
individuals who least graduated high school or progressed further was 88.8% (compared to 82.8% in the present study) (Shah et al., 2010).

The NVS was originally validated for oral administration with oral answers from participants in a one-on-one setting (Appendix H), but it was modified to include a paper-based answer sheet for administration in a group setting in this study (Appendix I). Previously, the NVS has been modified to a completely paper-based format, in a study that tested the feasibility of incorporating it into medical office visit paperwork (Welch, VanGeest, & Caskey, 2011). To discourage participants from using our paper-based answer sheet for calculations or note taking, participants were asked to write their answers only on the answer sheet and write them on a designated line. With the oral, validated format of the NVS, it is not possible to take notes or do written calculations. To assess the feasibility of administering the NVS in a group setting, the following aspects were observed and recorded: participants’ time required for administration, requests for clarification or additional instruction, ability to complete the answer sheet, comfort level, and any potential threats to validity.

Readability refers to the predicted difficulty of reading a printed material based on its vocabulary, word length, and sentence length (Friedman & Hoffman-Goetz, 2006). To answer RQ 1, five readability measures (Table 2) were used in this study: the Flesch Reading Ease Scale (Flesch, 1948), Flesch-Kincaid Reading Grade Level (Kincaid, Fishburne, Rogers, & Chissom, 1975), Simplified Measure of Gobbledygook (SMOG) (McLaughlin, 1969), Gunning Frequency of Gobbledygook (FOG) (Gunning, 1952), and the Fry Readability Graph (Fry,
1968). These formulas were selected based on their widespread use in public health research and practice, which will allow for comparison of our results to previous research. In addition, the SMOG provides a particularly useful grade level estimate at which 100% of readers can be expected to understand the text (McLaughlin, 1969). Each formula was used to calculate readability of the MA BMI letter (Appendix J) and educational materials sent home to parents, which include nutrition information (Appendix K), physical activity information (Appendix L), and frequently asked questions about BMI (Appendix M). All formulas were calculated by hand using published instructions from the original authors. Partial sentences, phone numbers, and website addresses were not included in the sentence and word counts.

In addition to readability formulas, an updated Suitability Assessment of Materials (SAM) was used to evaluate the cultural appropriateness of the letter and educational materials for the target audience (Doak et al., 1996). The original SAM evaluates 22 factors within the categories of content, literacy demand, graphics, layout, typography, learning stimulation, motivation, and cultural appropriateness. It yields a percentage score that denotes whether the material is considered superior, adequate, or not suitable and suggests areas where revision is needed (Doak et al., 1996). The SAM has been recently updated to the SAM+CAM (Appendix N) to include additional criteria such as comprehensibility, behavior theory, and presentation of numeric content (Helitzer, Hollis, Cotner, & Oestreicher, 2009). These additions were reviewed and approved by the instrument’s original developers (Helitzer et al., 2009). The
updated SAM+CAM version was used in this study to provide a more complete evaluation of the educational materials.
Quantitative Methods

Quantitative methods were used to evaluate participants’ demographic backgrounds and examine RQs 1 & 2. Using the demographic survey, data were collected on participants’ age, gender, number of children, ages of children, race, ethnicity, educational level, and language spoken most often at home, and univariate descriptive statistics (means, standard deviations, and frequencies) were calculated. To answer RQ 1, the five selected readability formulas were used to calculate reading grade-level estimates from the number of words, syllables, and sentences in the BMI letter and educational materials. The range and distribution of grade-level results was identified for each document.

To answer RQ 2 (Specific Aim 2a), the adapted version of the NVS was scored from 0-6 according to established scoring procedures. The score range and frequencies were examined. Bivariate analyses were also conducted with NVS scores and language, gender, education, and ethnicity. Quantitative methods were also used to address a portion of Specific Aim 2b, the feasibility of the NVS in a group setting. To evaluate the time required for administration, the number of minutes required for each group was noted from audio recordings, and univariate descriptive statistics (range, mean, and standard deviation) were calculated.

Qualitative Methods

Qualitative inquiry is well suited for examining phenomena that are not easily measured, such as culture, meaning, and perception, and for explaining reasons underlying observed outcomes (Harris et al., 2009). Both situations
applied in this study; for example, reasons for parents’ dislike of particular weight terms were examined. Qualitative research can also generate hypotheses and theories (Patton, 1990). This qualitative study helped to identify reasons for the BMI letter’s lack of efficacy in quantitative research (e.g., Madsen, 2011) and explore how the BMI letter could be made more effective. In this study, qualitative methods were used to answer RQs 3 & 4. Focus groups were conducted with a convenience sample of parents. Focus groups were chosen over individual interviews because of the potential for group dynamics and the observed group interaction to yield additional useful information (Harris et al., 2009). Attention was given to developing a standard method and detailed focus group guide (Appendix O) that employed objective questioning techniques to avoid biasing respondents (Harris et al., 2009).

Eight focus groups made up of parents of children beginning the MIGHTY program were used to gather information relevant to RQs 2-4 and ended with administration of the modified NVS to each group. Two to six parents participated in each group. Each focus group was held for about one hour and was audiotaped with consent using multiple digital recorders. Incentives included a healthy snack, bottled water, and a $20 Big Y gift card for each participant. A poster containing guidelines for maintaining privacy and promoting respectful dialogue was displayed. A Baystate research assistant was present to take notes on nonverbal language observed, and this author recorded notes and observations immediately following each group.
Focus groups were facilitated by this author using a semi-structured focus group guide (Appendix O), which contains questions previously used with two focus groups of low income, ethnically diverse adults recruited through the Worcester office of the Expanded Food and Nutrition Education Program (EFNEP). These two focus groups were held at a transitional home for women in recovery from substance abuse and at a community family health service center. The focus group guide pretested questions referring to weight communication for both adults and children, and included words tested for participant reactions in the current study (heavy, BMI, overweight, and obese) (Gustamachio, 2011).

This focus group guide used in this study was specifically designed to elicit parents’ responses to weight-related language used with children and the Massachusetts (MA) BMI letter. To stimulate engagement, the focus group discussion included showing participants a set of images depicting a continuum of weight (Appendix O) and ten terms used to describe children’s weight (Appendix O) that have been tested in a recent online survey (Puhl et al., 2011). Copies of the images were given to each participant. Each weight-related term was printed on an 8 ½ x 11-inch paper, enclosed in a plastic sleeve, and held up one by one to elicit participants’ reactions. The order of the terms was randomly determined for each focus group. The focus group guide was adapted for this study by focusing only on language used with children and changing the list of words to match recent research (Puhl et al., 2011). This focus group guide was pilot tested with a group of graduate students to plan for timing and pacing.
To stimulate dialogue about the BMI letter during the focus groups, and to avoid using any language that might affect later questions, a completed version of the state BMI letter (MA DPH, 2009) was distributed to each participant (Appendix P). Our letter contained BMI data for a fictional child to facilitate discussion. This portion of the focus group employed cognitive interview techniques to direct discussion of thoughts and feelings about the BMI letter and to explore participants’ understanding of the letter. Parents were asked to look at sections of the letter demarcated by a blue dotted line and describe aloud what the information was telling them. Cognitive interviewing has previously been used in developing nutrition surveys (Wallen, Feldman, & Anliker, 2002) and messages (Carbone et al., 2002) to learn about how individuals attend to and process information. Finally, the NVS was administered. To decrease potential “test taking” anxiety, the NVS was presented as an opportunity for the researchers to find out how easy or hard it was to understand a food label.

Human Subjects Protection

This research study has been approved by the University of Massachusetts Institutional Review Board and by the Baystate Medical Center Institutional Review Board (Appendix Q). Informed consent (Appendix C) was obtained from all participants during recruitment. Key points of the informed consent were summarized orally to prevent limited literacy skills from impacting participant understanding. Parents were reminded throughout recruitment and the focus groups that their participation was voluntary and they were permitted to leave at any time without negatively affecting their association with Baystate. All
files containing identifying information were transferred between IRB-approved project team members using encrypted email. Similarly, digital recordings were uploaded to the UMass translation center from a password-protected computer through an encrypted file transfer protocol (FTP) site.

**Analysis**

In general, quantitative analysis was used to examine participant demographic information and answer RQs 1 & 2. For RQ/Specific Aim/Hypothesis 1, all readability formulas and the SAM+CAM were calculated by hand using published instructions from the original authors. The reading grade-level estimates were not averaged.

For RQ 2 (Specific Aim/Hypothesis 2a), the adapted version of the NVS was scored from 0-6 according to established scoring procedures. The score range and frequencies were examined. Bivariate analyses were also conducted. Chi-square and Fisher’s exact tests were used to explore the relationship between NVS scores and gender (male/female), ethnicity (Hispanic/Latino or not), education, and language spoken most often at home (English/Spanish). Microsoft Excel 2008 for Mac was used to calculate univariate statistics and IBM SPSS Statistics 20 for Windows was used for Fisher’s exact and Chi-square tests. Because the Chi-square approximation may not be valid for 2 x 2 tables that have df = 1, the Yates correction was used (Pagano & Gauvreau, 2000).

Education was assessed in two ways: by dichotomizing participants into categories based on high school (grade 12) or lower versus some college or higher, and by dichotomizing participants into categories based on finishing high
school (grade 12) or higher versus not finishing high school. The potential association of NVS scores with the former educational level categories was assessed using the Chi-square test and Yates correction; all others were tested using Fisher’s Exact due to the size of the expected values. For all tests, NVS scores were dichotomized into two groups: adequate health literacy (scores of four, five, or six) and low health literacy (scores of one, two, and three).

For RQ 2 (Specific Aim/Hypothesis 2b), feasibility was assessed by observing and noting participants’ time required for administration, requests for clarification or additional instruction, ability to complete the answer sheet, comfort level, and any potential threats to validity. Time required was evaluated using quantitative analysis (range, mean, and standard deviation). All other aspects of feasibility were examined by collecting relevant participants comments from the transcripts and notes from the focus group facilitator and notetaker.

Qualitative analysis was used to answer RQs 3 & 4. For all qualitative analysis, focus group recordings were professionally transcribed verbatim by the UMass translation center. This author listened to the full audio for each focus group to edit transcriptions for accuracy, including matching specific participants with their comments. Content analysis of transcriptions and additional notes was conducted to organize the text according to codes based on the original focus group guide and to identify emergent themes. This content analysis was organized using QSR NVivo 9 software. This author was the primary reviewer of the qualitative data, but other members of the research team took part to check for consistency.
Specifically, RQ 3 (Specific Aims 3a & 3b) was analyzed by coding the transcripts for all references to participants’ reactions to weight terms/phrases and their stated preferences for weight terms/phrases. Themes that emerged during the coding process were used to address Specific Aim 3c, the identification of terms and phrases that may be used to effectively and respectfully communicate with parents about their children’s weight. RQ 4, which addressed how selected parents/caregivers respond to the MA BMI letter, was analyzed using a similar process of coding transcripts and identifying emergent themes related to parents’ reactions (Specific Aim 4a), parents’ understanding (Specific Aim 4b), parents’ actions (Specific Aim 4c), and parents’ desires for specific types of educational information (Specific Aim 4e). Specific Aim 4d, to identify ways the BMI letter could be made more effective and respectful, was examined in the context of all relevant themes emerging from the qualitative analysis, as well as the readability and health literacy results (RQs 1 & 2).

**Summary of Research Methods and Analyses**

This research was a qualitative study of parents/caregivers of school-age children seeking treatment for weight management. These parents had a school-age (8- to 14-year-old) child referred by a pediatrician to a family-based, intensive weight management program based on having a BMI at or above the 95th percentile. Demographic information was collected from parents with a survey. Eight audio-taped focus groups (each with two to six participants) totaling 29 parents/caregivers were conducted. A semi-structured focus group guide was used to conduct focus groups to elicit parents’ responses to weight-related
language and the Massachusetts (MA) BMI letter. As a group, the focus group participants also completed a validated Newest Vital Sign health literacy assessment. Readability assessment of the MA BMI letter and educational materials sent home to parents was conducted separately using five commonly available readability formulas. Quantitative methods and analyses were used to answer RQs 1 & 2, and qualitative methods and analyses were used to answer RQs 3 & 4.
CHAPTER 9

RESULTS

Demographics

Twenty-nine adults participated in eight focus groups and completed a demographic survey (Table 3). The convenience sample was predominantly female (83%) with a mean age of 41±9 years (Table 3). Ages of the parents/caregivers ranged from 25 to 61 years. The majority of participants (72%) were 30-49 years old. The number of children through age 19 living in each participant’s household was also assessed (mean 2±1). Two participants’ answers regarding the number of children living in the household and their ages were excluded from the analysis because the number of children was not consistent with the number of ages provided. Ten participants (37%) had only one child living with them. Most children (83%) were between the ages of 6 and 15 years, with a mean age of 11±4 years.

Two questions assessed race/ethnicity. Three participants chose not to respond to the questions. Of those who responded, 17 individuals self-identified as Hispanic/Latino (59%). Fewer participants (n=20) responded to the question that asked for the race category or categories with which they identified. Of those responding, 10 identified as Black or African American (33%) and 11 identified as White (37%). The total of 21 responses rather than 20 reflects the one individual who selected both Black/African American and White categories. No participants identified as American Indian or Alaskan Native, Asian, or Native Hawaiian or other Pacific Islander. One individual did not answer the question asking for the
language spoken most often at home. Of those responding, 23 spoke English (79%) and five spoke Spanish (17%) most often.

Education level was assessed by asking participants to write in the highest educational grade they had completed at the time of the survey. Education ranged from ninth grade to a college degree. Five participants (17%) did not complete high school, 11 (38%) graduated high school or completed a GED, 10 (34%) completed some college or an associate’s degree, and three (10%) completed college. Household income was not included on the demographic survey because it was not collected in the EFNEP pilot study.

The relationship of parents/caregivers in the study to their children participating in MIGHTY was not assessed through the demographic survey, but focus group transcripts and notes on the topic were compiled. Among the 29 participants, five were fathers, 19 were mothers, four were grandmothers, and one was a caregiver.

**Research Question 1: Readability**

*RQ 1. What is the readability level of the Massachusetts (MA) BMI letter and educational materials sent home to parents/caregivers?*

Readability varied based on the formula used and the educational material assessed (Specific Aim 1). The BMI letter provided by the MA DPH was assessed for readability, as well as four educational materials intended for inclusion with the letter: 1) *Help Your Kids Eat Healthy at Home* (“Eat Healthy”), 2) *Give Your Kids the Right Amount of Food* (“Right Amount”), 3) *Your Child Needs to Be Active Every Day* (“Be Active”), and 4) *Frequently Asked Questions*
about Body Mass Index (BMI) Screening (“FAQs”). Some materials met or exceeded the hypothesized reading grade level of sixth grade or lower (as recommended by Doak et al., 1996) based on all formulas, whereas others were estimated to be both below and above the hypothesized level, depending on the formula used (Table 4). All formulas produced reading grade-level estimates, with the exception of Flesch Reading Ease, for which grade-level equivalents are noted.

The BMI Letter scored at approximately a seventh-grade reading level using the Fry (7), FOG (7.5), and SMOG (7) formulas. However, the Flesch Reading Ease and Flesch-Kincaid formulas estimated the letter at 84.5 (grade 6) and 5.1, respectively. The “Eat Healthy” and “Right Amount” educational materials received similar grade-level estimates. The “Eat Healthy” estimates ranged from approximately third to seventh grade (Flesch-Kincaid: 2.9, Fry: 4, Flesch Reading Ease: 91.1 [grade 5], FOG: 5.8, SMOG: 7). The “Right Amount” estimates ranged from approximately third to sixth grade (Flesch-Kincaid, 2.9, Fry: 3, Flesch Reading Ease: 94.6 [5], FOG: 6, SMOG: 6). The “Be Active” educational material scored higher, with estimates ranging from seventh to ninth grade (Flesch-Kincaid: 6.8, Fry: 8/9, Flesch Reading Ease: 69.7 [8-9], SMOG: 9, FOG: 9.2). The “FAQs” educational material scored highest of all the educational materials. Grade-level estimates were all higher than sixth grade and ranged from seventh to tenth (Flesch Reading Ease: 71.9 [7], Flesch-Kincaid: 7.5, SMOG: 8, Fry: 10, FOG: 10.1). The updated Suitability Assessment of Materials (SAM+CAM) (Helitzer et al., 2009) scores all materials within one of three
categories: superior (>70%), adequate (40-69%), or not suitable (0-39%). The BMI letter and all educational materials were considered adequate, scoring from 48-66% (BMI letter: 60%, “Eat Healthy”: 62%, “Right Amount”: 66%, “Be Active”: 62%, “FAQs”: 48%).

**Research Question 2: Health Literacy**

*RQ 2. What is the health literacy level of selected parents/caregivers in Massachusetts who are part of the intended audience of the BMI letter?*

**Newest Vital Sign Scores**

The Newest Vital Sign (NVS) scores supported Hypothesis 2a, that parents participating in MIGHTY would have a range of health literacy skills based on NVS results. On a possible scale of 0 to 6, scores ranged from 1 to 5 (Table 5) (Specific Aim 2a). A total of 12 participants (41%) received a score of 1, 2, or 3, indicating less than adequate health literacy (Figure 1). Five of those participants (17%) received a score of 1, indicating a high likelihood (50% or more) of limited literacy. Five participants received a score of 2 and two participants received a score of three, indicating that 24% of the sample had a possibility of limited literacy. The remaining 17 participants (59%) scored within the range of adequate literacy (4, 5, or 6).

**Bivariate Categorical Tests**

Potential associations between NVS scores and education, gender (male/female), ethnicity (Hispanic/Latino or not), and language spoken most often at home (English/Spanish) were assessed using 2x2 tables. Education was assessed in two ways: by dichotomizing participants into categories based on
high school (grade 12) or lower versus some college or higher, and by
dichotomizing participants into categories based on finishing high school (grade
down) or higher versus not finishing high school. The potential association of NVS
scores with the former education level categories was assessed using the Chi-
square test and Yates correction; all others were tested using Fisher’s Exact due
to the size of the expected values. For all tests, NVS scores were dichotomized
into two groups: adequate health literacy (scores of 4, 5 or 6) and low health
literacy (scores of 1, 2, and 3).

No tests yielded significant results. In particular, no trend was observed
using the Fisher’s Exact test for gender or ethnicity (P=1.000 for both). Although
not significant (P=0.624), a trend toward Spanish language and low health
literacy was observed. Among those speaking Spanish at home, 60% of
participants received an NVS score indicating low health literacy, compared to
39% of English-speaking participants. Similarly, a nonsignificant trend toward
lower education and low health literacy was also observed. For grade ≤12 versus
some college or more (P=0.154), 56% of those with less education had low
health literacy, compared to 23% of individuals with more education. Likewise, for
grade<12 versus grade≥12 (P=0.130), 80% of those with less education had low
health literacy, and only 33% of those in the category of high school graduates
had low health literacy.

Feasibility of the Newest Vital Sign in a Group Setting

Subjective evaluation of the NVS administration process supported
Hypothesis 2b, that it is feasible to administer the Newest Vital Sign to parents in
a group setting. Feasibility was assessed by observing and noting participants’
time required for administration, requests for clarification or additional instruction,
ability to complete the answer sheet, comfort level, and any potential threats to
validity (Specific Aim 2b). Among the eight groups, time required to completely
administer the NVS ranged from approximately 5.8 to 8.6 minutes based on
review of the audio recordings (mean 7.4±1.1 minutes). Most often, requests for
clarification were requests to repeat all or a portion of a question. In a few
instances participants asked a question that would assist them in correctly
answering the question, and in such cases this author took care to address their
question without providing additional information. For example, in response to
question five about food allergens, one individual asked, “It all depends on the
flavor, right? It doesn’t say what flavor ice cream.” This author responded that he
could write down his best thought based on the information he had in front of
him. All participants attempted to complete the answer sheet and were instructed
that leaving an answer blank was OK if they did not know it. Across the entire
sample, 23 of 174 (13%) answer lines were left blank. The maximum number of
lines left blank on any participant’s six-question answer sheet was four, and this
was the case for one participant only.

Comfort level was subjectively assessed based on participants’ comments
and nonverbal cues. Some participants voiced their dislike of the seemingly
academic task in a lighthearted manner, with comments such as “This is like
math class,” “I’m horrible at math,” or “I just came out of work with [doing] math.”
At times, some participants commented that they did not know an answer or they
did not know how to do a calculation. This author reminded them that it was OK if they did not know answer, they did not need to worry, and they could leave the line blank if they desired. No individuals appeared to display significant distress or embarrassment, and no one asked to be excused from completing the task. In earlier groups, some participants expressed disappointment that they could not review the correct answers immediately after taking the NVS (to protect the validity of the ongoing study). Thus, future groups were assured they would receive an answer sheet with explanations at their next MIGHTY class.

Potential threats to validity were noted. This author and a notetaker observed each NVS administration session, and only one case of egregious copying from a neighbor appeared to occur. Participants were instructed to do their own work because we were seeking to find out what each person was thinking. In other instances, participants used aids in the calculations that would not have been available in the validated oral version of the NVS, which by default requires that calculations be done without paper, pencil, or calculators. One person attempted to use his cell phone and apparently its built-in calculator during the NVS, but this author asked him to stop and asked him to answer with “just what you would come up with if you were doing it in your head.” Participants were also instructed to write only their answers on the answer sheet to avoid note-taking or paper-and-pencil calculations. Five instances of brief note-taking or calculations were observed on answer sheets, and two additional instances on supplemental focus group materials that were collected. However, most participants responded to questions as directed.
Research Question 3: Weight Communication

RQ 3. How can information about children’s weight be effectively and respectfully communicated to parents/caregivers?

Reactions and Preferences Regarding Weight Terms and Phrases

Themes emerging from focus group results were used to answer RQ 3, regarding how information about children’s weight can be effectively and respectfully communicated to parents/caregivers. In particular, parents’ reactions to and preferences for terms and phrases used in describing children’s excess weight were examined (Table 6) (Specific Aims 3a & 3b). The 10 weight words presented to parents (Puhl et al., 2011) were examined in detail: weight, weight problem, unhealthy weight, obese, fat, extremely obese, high BMI, overweight, heavy, and chubby.

Of the 10 words, the theme of participants preferring weight, weight problem, and unhealthy weight emerged. These words were identified as terms and phrases that may be used to effectively and respectfully communicate with parents about their children’s weight (Specific Aim 3c). Parents responded only in a neutral or favorable manner to the word weight, to which one parent said, “That’s not bad. I don’t see that as a bad word,” and another noted, “We all have a weight.” Weight problem was generally accepted because it “could be just a few pounds or it could be a hundred pounds,” it “could be either skinny or heavy,” and it “could be either a low weight or high weight.” Parents made similar comments regarding unhealthy weight. The reasons parents preferred weight problem and unhealthy weight were consistent with the theme of “normalizing.”
Participants tended to normalize their children’s excess weight in a variety of ways, talking about the increasing prevalence of obesity in their communities and on a national and international scale. The acceptance of unhealthy weight was also supported by parents’ preference for discussing children’s weight in their context of their own health and health behaviors. For example, one participant said, “I think instead of saying, ‘We’re going to give you a referral to the obesity clinic,’ they should say, ‘We’re going to give you a referral to someone that’s going to help you eat healthier and live a healthier life and show you ways to be more active.’” Related to this observation, a theme emerged of parents being motivated to make changes by concern for their children’s health. In particular, parents said their children’s risk of future diabetes or heart problems motivated them to take action.

Also among the 10 words presented to parents, the terms obese, fat, and extremely obese were clearly viewed as most offensive. The theme of parents’ preferring these words the least was identified. In describing their reactions to obese, fat, and extremely obese, parents used words such as hate, nasty, mean, scary, and brutal. While crying, one mother recounted a story of a health professional telling her she was going to die because of health problems related to her weight, a memory that the word extremely obese prompted. This experience was an example of participants’ tendency to reflect on their own weight problems and related encounters in the health care system, despite the stated focus on their children. In her reaction to extremely obese, another mother said, “I’ve been there, not [my daughter] yet, but I’ve been there and yeah, it
hurts.” Although the reactions to *obese* were generally negative, mixed reactions were also voiced (Table 7). These reactions to *obese* ranged from offense or disgust (“I hate that word”) to concern, acceptance, and even motivation. For example, one father said, “I wouldn’t feel bad about [the word *obese*]. It would just let me know that I need to change something in my child.”

The theme of “mixed reactions” characterized parents’ responses to the terms *high BMI* and *overweight*. Many of the parents who considered *high BMI* acceptable said so because they did not think their child would understand the word. Negative reactions to *high BMI* stemmed from concern over the effect of the word on a child’s self-esteem, parents’ confusion over the meaning of BMI and its calculation, and questions about the validity of BMI as a measure of excess weight. Regarding a child’s self-esteem, one participant said, “For a child this scares me just because they can get fixated on this … it could bring a child to having a very bad self-image.” Results regarding the validity of BMI will be discussed further with respect to RQ 4, parents’ responses to the BMI letter. For the term *overweight*, many parents voiced neutral reactions (“alright,” “appropriate,” or “OK”), and mentioned that it was preferred over other words, such as *obese*. Similar to objections to the term *high BMI*, most negative reactions to *overweight* dealt with its use in the presence of children, who may be upset by the term.

The term *heavy* did not generate a large amount of discussion, apart from the theme that some parents thought *heavy* wasn’t appropriate to describe a person’s size and was more suited to describing an inanimate object. For
example, one participant said, “I think that’s so, like, obscure … because heavy could be a bag of rice.” Participants demonstrated conditional acceptance of chubby, with some parents saying the term was OK when only they used it or when children were young. One parent explained, “When they get older, something happens. They’re like, don’t call me that.”

**Patient-Provider Communication**

In addition to specific words and phrases used for describing children’s weight, parents’ experiences with patient-provider communication regarding their children’s weight were also examined. In this context, the theme of “concern for children’s health” emerged again, with many parents saying that any discussion of children’s weight with health professionals was OK if it was motivated by concern for the child’s health. One said, “Any kind of feedback is good feedback.” Participants also commented that it was better to know now if their children was at risk for a health problem: “You’d rather know than to wait and then something else goes wrong somewhere, being overweight can end up to be a health issue.”

The theme of mixed reactions to past experiences discussing children’s weight with a health care professional was identified (Table 8). Among participants’ reasons for negative reactions, some parents—and at times, their children—did not like the words physicians used to discuss the child’s excess weight, such as obese. For one child’s parents, it was clear that no matter what words the doctor used, the experience would be upsetting. In another case, a participant described a doctor who told her child he was “fat” for his age. After voicing her objections to the doctor’s use of the word fat, she said the doctor told
her that was his “way of making him understand that he needs to lose weight.” Although parents did not give specific examples of alternative words to use, some terms among the 10 words discussed in the previous section (weight, weight problem, and unhealthy weight) were overall more preferred by participants. One parent also had a problem with her son, who reacted to an initial weight conversation at the doctor’s office by deciding to stop eating, and she needed the physician to explain the problem to him again so he understood. In addition to word choice, a second major theme emerged from parents’ negative experiences: Physicians’ responses to weight concerns were seen as inadequate. One parent explained, “I had a concern with my son’s previous pediatrician that I had concerns about my son’s weight, and he said he’ll grow out of it, he’ll grow out of it … we changed the pediatrician and the first thing this new pediatrician said to us was the weight issue.” She was angry that they “could have nipped this in the bud” years ago.

Among parents with positive responses to their interactions with health professionals, themes included the physicians using words deemed appropriate; physicians providing helpful tips, feedback, and support; and physicians adequately addressing possible medical issues related to the child’s excess weight. Regarding appropriate words, one participant explained, “My daughter’s pediatrician, they use weight as a word, not obesity or fat, you know, having weight issues and made her feel like a bigger part, saying that a majority of kids these days have weight issues: lower or higher.” Examples of helpful feedback included specific nutrition advice. Support included one mother’s experience: “My
son ended up losing some weight, and the doctor gave him a pat on the back. He said good and good job Mom.” In one case, a helpful exchange was initiated by the child when he brought up the idea of losing weight and exercising to the physician, and a productive discussion followed. In addressing possible medical issues related to the child’s weight, participants were pleased when a physician investigated the effects of a medication on the child’s appetite, sent the child for a blood test to measure blood sugar levels and diabetes risk, and referred them to an endocrinologist. Parents also responded well to visits with nutritionists, citing their helpful nutrition advice and positive interaction with the children.

The variety of positive experiences with health professionals informed the theme of desired traits in providers. Parents wanted health professionals to be positive and sensitive with their children, and to explain concepts in ways they could understand. For example, one father said, “Don’t single [my child] out. Don’t make him feel like he has a problem, a big – a disease – you know?” One parent wanted the doctor to discuss the child’s weight problem with her and not the child first, so they could talk about how to explain it to the child together. Another parent advised, “They need to go lower on the older terms they use, like the term obese … They say you gotta eat healthy, but tell them exactly what it is, like show them pictures.” In this case, the endocrinologist’s use of a plate to model healthy eating behaviors was considered helpful.

In general, the examination of weight terms and patient-provider communication yielded results describing parent preferences in this group. Weight, weight problem, and unhealthy weight were clearly preferred more than
obese, fat, and extremely obese. High BMI and overweight generated mixed reactions. Reasons for positive or negative reactions to patient-provider communication about children’s weight were related to word choice, sensitivity, feedback, and investigation of potential medical causes/consequences of the child’s excess weight.

Research Question 4: Responses to the BMI Letter

RQ 4. How do selected parents/caregivers respond to the MA BMI letter?

Initial Reactions to the Letter

When examining parents’ initial reactions to the Massachusetts BMI letter (Specific Aim 4a), three major themes emerged: the letter was not communicating new information; the letter was acceptable and could be helpful; and the validity of BMI as a measure of children’s excess weight was questionable (Table 9). In reference to the first theme, one parent said, “Yeah, I mean I would look at [the letter], but it’s not telling me anything that I probably don’t already know.” Another parent had a stronger response, saying, “I’ve gotten something like this [letter] … I was kind of upset ‘cause I said, ‘Who are these people?’ I take my kids to the doctor so I already know where they stand.” Of those who thought the letter was acceptable or helpful, parents said it was good to be aware of potential weight-related concerns about their child’s health and the new BMI policy was welcome compared to a lack of notification in previous generations. For example, in reference to having previously received the letter about their own child, one participant said, “[The letter] only encouraged me to move … I didn’t have a problem with it … it only helps me.” Likewise, another
said, “It’s actually good that they do it because you get to see – back when you’re younger they never did this so – you just get to see where they compare and where they should be.”

Among the parents who questioned the validity of BMI as a measure of children’s excess weight, some parents focused on the sentence in the letter regarding muscle mass. One participant said, “The one thing that I do like about this letter is that it does say that BMI cannot tell the difference between muscle and fat.” Another stated that “a kid with muscle is not obese” and described his children’s physical activity regimens that led them to be “thicker” because of muscle. Other participants disagreed with BMI because it only considered height and weight. These parents did not like the fact that a child’s build/heredity was not taken into account. Rather than relying on BMI, a number of parents evaluated children’s weight status by making informal comparisons to other adults and children they knew. One participant recounted an experience that was characteristic of this type of evaluation: “I had some friends come to me and tell me, ‘Do you believe the doctor said my child is overweight?’ and their kid’s next to mine … they’re crazy, they’re not overweight.”

**Reactions to BMI Screening in Schools**

Responding to the BMI letter prompted broader discussion of the BMI screening and notification being implemented in schools statewide. Parents voiced mixed reactions to the BMI policy (Table 10). Positive themes were the letter’s potential to be helpful and motivate change. These themes were discussed in parents’ initial reactions. As one parent noted, “This is very positive,
and I think everybody should get it and get screened … I’m just glad the school noticed and they’re out there to help the kids with their weight.”

Conversely, one negative theme was that some parents did not consider BMI screening and notification to be part of the school’s role. One said that “… it really should be coming from a physician and not a nurse from a school,” and another voiced distrust of the school nurse. Other negative themes stemmed from the impact of the BMI screening process and the letter itself on children’s self-esteem. Regarding the process, not all parents were convinced that the “little check-ups” done in school to measure weight were carried out in a sensitive manner. State law for carrying out the screening mandates “direct, confidential notification” in writing to parents/guardians; the associated guidelines from the Department of Public Health specify that letters should not be sent home with students (MA DPH, 2009). However, of the 15 focus group participants who said they had received a BMI letter, five (33%) mentioned that their child brought home a BMI letter with them from school. This study was not designed to assess the extent to which BMI screening practices adhere to the law, but the experience of these parents lends support to the group’s privacy concerns. One parent said, “When my son showed [the letter] to me – Mom, I’m not this way am I? – it already started the situation.” Two parents of children with autism were specifically worried about the possibility that their child – who would “go by the textbook dictionary” or “loves to look words up” – would be scared or panic when interpreting words such as obese. Consistent with the theme of children’s self-
esteem, parents were also concerned about the screening process potentially influencing weight-related teasing from peers.

**Understanding of the Letter**

Three themes regarding parents’ understanding of the BMI letter were identified (Specific Aim 4b): correct recognition of the letter’s request (seek medical attention), some confusion about interpreting the top half of the letter (child’s weight status), and some confusion about interpreting BMI (Table 11). Parents recognized that the letter was asking them to seek medical attention for an overweight/obese child. However, some parents had problems interpreting the top portion of the letter. This section, above the blue dotted line, described the child’s weight status (overweight for the sample child used) and included the colored bar. Not all parents realized on their own that the sample child was above a normal weight. Errors included focusing on the large, green portion of the colored bar and therefore assuming the green color meant the child’s weight was healthy, as well as interpreting percentiles on the colored bar as pounds. For example, one parent stated that the sample child “has a healthy weight because it’s green” and another said, “It tells me that after 85 pounds and his height is going to be overweight, and obviously after 95 pounds he’s going to be obese.” As discussed previously, a number of parents were confused about the term BMI, calculation of the index, and its interpretation.

**Responses to Receipt of the Letter**

Parents were asked to predict what they would do in response to receiving the BMI letter, but most who answered this question had already received a BMI
letter about their child. Parents reported a variety of actions they took as a result of receiving the BMI letter, including taking their child to the doctor, talking to their child about making different food choices, or not taking their child to the doctor because they were aware of the problem (Specific Aim 4c). As one parent described, “What we did is look at the results of where it was – where she stood, you know, overweight, obese – and then we called the doctor, made her physical stuff.” Regarding food choices, another said, “I started on my kids, you know, you got to cut down on this, you got to cut down on that … [My kids] weren’t happy about this so I just put the letter in some papers and then didn’t worry about it any more.”

**Helpful Information to Accompany the Letter**

Parents recognized barriers to making changes for their child in response to the information communicated in the BMI letter (Table 12). Themes included their lack of control over food choices offered at school, the cost and availability of safe opportunities for physical activity, and the cost of taking children to a physician for their weight. One parent also mentioned that he did not have time to look for information about weight management on the Internet, as suggested in the BMI letter, while another noted that not all parents have Internet access. These barriers were consistent with parents’ recommendations for additional information that could accompany the BMI letter to support positive behavior change (Specific Aim 4e). Parents wanted specific information about nutrition and healthy eating for children, including portion sizes, recipes, strategies for promoting heathful foods, and culturally-appropriate food options. Information
about local opportunities for physical activity was also desired. One parent explained, “A lot of people, they don’t know what is offered for the kids. Like at my son’s school, they don’t have any after-school activities, all they have is arts.” Inclusion of information and contacts with the letter, rather than only Internet resources, was suggested. Other participants also recommended giving parents information in both English and Spanish.

**Summary of Results**

In conclusion, the results of this study yielded information about the readability of the BMI letter, the health literacy levels of selected parents/caregivers, parents’ preferences for weight language to describe children, and responses to the MA BMI letter. Readability varied based on the formula used and the educational material assessed. Some materials met or exceeded the hypothesized reading grade level of sixth grade or lower based on all formulas, whereas others were estimated to be both below and above the hypothesized level, depending on the formula used (Table 4). On a possible scale of 0 to 6, a total of 12 participants (41%) received an NVS score of 1, 2, or 3, indicating less than adequate health literacy (Figure 1). Subjective evaluation supported the feasibility of administering the Newest Vital Sign to parents in a group setting. Focus group participants preferred the terms *weight*, *weight problem*, and *unhealthy weight* the most for describing their children’s weight (Table 6). Parents voiced mixed reactions to the BMI letter (Table 9) and BMI screening in schools (Table 10), as well as many levels of understanding of the BMI letter (Table 11).
CHAPTER 10
DISCUSSION

Demographics

Demographic data showed that the study population was largely female and predominantly Hispanic/Latino. However, the response rate for the race question on the demographic survey (69%) limits further description of the participants. Of those responding, approximately half identified as Black/African American and half as White. On average, this convenience sample had higher levels of education than expected prior to recruitment. Based on crude comparisons to U.S. Census data, the proportion of participants who did not complete high school (17%) was slightly above the national average (13%) (U.S. Census Bureau, 2012). In addition, the proportion of participants who graduated high school (38%) or completed some college or an associate’s degree (35%) were above the national average (31% and 26%, respectively). The proportion of bachelor’s degrees attained in the United States exceeded that of the study population (19% versus 10%, respectively). The absence of income data limited the ability to further describe the socioeconomic status of study participants.

Readability

Readability results for the BMI letter appeared to be mixed with respect to the hypothesized level of sixth grade or lower. Although the letter was at or above a seventh-grade level according to the Fry, FOG, and SMOG formulas, it was categorized at sixth- and fifth-grade reading levels with the Flesch Reading Ease and Flesch-Kincaid formulas, respectively. This difference is consistent with
previous research on the Flesch-Kincaid formula. Others have noted that the formula may underestimate the reading level of written materials by approximately two grades (Burke & Greenberg, 2010). Conversely, the SMOG provides a particularly useful grade level estimate at which 100% of readers can be expected to understand the text (McLaughlin, 1969). Thus, the majority of available evidence suggests the BMI letter does not reach the suitable readability level of sixth-grade or lower (suggested by Doak et al., 1996 for health care instructions).

Readability results were more consistent for the educational materials associated with the letter. All formulas yielded a reading grade level of six or lower for the “Right Amount” material. With the exception of the SMOG formula’s seventh-grade estimate, all other formulas scored the “Eat Healthy” material below sixth grade. “Be Active” and “FAQs” consistently scored above the sixth-grade level using all formulas. “FAQs” in particular scored a high of 10 and 10.1 with the Fry and FOG formulas, respectively. Therefore, the two nutrition-related educational materials appeared to remain within a suitable reading level, but the physical activity and frequently asked questions materials did not.

The five readability formulas were useful to provide a rough assessment of the educational materials’ appropriateness for the intended audience. Selection of an appropriate level was defined at or below the sixth grade level for this study, but is subject to debate. For example, some research suggests a fourth- to eighth-grade level is an acceptable range (NIH Plain Language Initiative, 2002). According to MA law that mandates the BMI letter, “A report of each student’s
BMI and percentile, along with easily understood informational and explanatory materials provided or approved by the Department on BMI, healthy eating and physical activity shall be mailed or otherwise directly communicated in writing to the parent or legal guardian of the student …” (MA DPH, 2009). A standard for “easily understood” is not further defined. There is adequate evidence from these readability estimates to suggest that the “FAQs” educational material provided by the MA DPH and other materials, including the BMI letter, may not meet a reasonable standard for “easily understood.”

However, readability estimates alone cannot adequately predict whether educational materials will be easily understood by members of an intended audience. A major drawback of readability formulas is their inability to assess characteristics of written documents known to affect ease of use, such as grammar and syntax, background knowledge, cultural context, coherence, print size, type style, color contrast, and density of information (Bailin & Grafstein, 2001; Doak et al., 1996). For this reason, the updated Suitability Assessment of Materials (SAM+CAM) (Helitzer et al., 2009) was used. Although it relies to some extent on the judgment of the evaluator, the SAM+CAM provides a useful framework for evaluating a material based on 22 variables that describe its content, literacy demand, numeracy, graphic material, layout/typography, and learning stimulation/motivation. The SAM+CAM scores all materials within one of three categories: superior (>70%), adequate (40-69%), or not suitable (0-39%).

Using the SAM+CAM, the BMI letter and all educational materials were considered suitable, scoring from 48-66% (BMI letter: 60%, “Eat Healthy”: 62%,
“Right Amount”: 66%, “Be Active”: 62%, “FAQs”: 48%). None of the materials reached the level of superior, but specific variables with scores of 0 (not suitable) can suggest potential areas for improvement. For example, the BMI letter failed to give examples to explain or clarify difficult words or concepts, such as BMI, percentile, and screening. It also did not employ any techniques to invite reader interaction or persuade readers to change behaviors/practices. Persuasive techniques include the use of testimonials, repetition, symbols, or cultural values (Helitzer et al., 2009). The “Eat Healthy” and “Be Active” educational materials did not include a box or section of the material for summary/review of key points, and again, did not employ techniques for interaction or persuasion. The “Right Amount” material also did not include summary/review or persuasion, or any evident use of behavior change theories. Finally, similar to the BMI letter, the “FAQs” material did not give examples to clarify difficult words or concepts. It was also too lengthy and detailed, making it difficult to identify key points. The tone was neutral rather than encouraging with a focus on solutions; persuasion techniques were also absent.

These deficiencies suggest changes that could be made to the BMI letter and educational materials for improving suitability/comprehensibility. Concepts such as BMI/BMI percentile, which generated confusion among some focus group participants, could be briefly explained. Materials lacking a review of key points could have a summary box added, if necessary, to enhance comprehension. The “FAQs” educational material could be edited to contain only the most important points and written in plain language. Reader interaction,
which fosters interest, learning, and memory, can be accomplished by including questions to which the reader responds or by giving examples of questions the reader can ask a physician (Helitzer et al., 2009). The latter option would be particularly relevant to BMI and weight management.

One persuasive technique is using familiar values in message design (Helitzer et al., 2009). In the BMI communication process, the value of “health,” could be emphasized because parents’ concern for the children’s health emerged as a theme in this study’s focus groups. For example, a sample version of the Arkansas state BMI letter (Appendix R) introduces its message with the statement, “Many children in Arkansas have health problems caused by their weight” (Arkansas Center for Health Improvement, 2006). The letter also describes potential health problems that can be associated with a child’s excess weight, which are not included in the MA BMI letter. However, any proposed changes to the MA version should undergo usability testing with members of its intended audience. Overall, readability estimates and the SAM+CAM evaluation suggest the MA BMI letter and educational materials could benefit from changes to improve readers’ understanding and ability to take positive action.

Health Literacy

Newest Vital Sign Scores

Findings from the Newest Vital Sign supported the hypothesis that participants in this study would exhibit a range of health literacy skills, although no one received a score of 0. According to the NVS results, a significant proportion (41%) of the sample had a high likelihood or possibility of limited
literacy. This proportion of limited health literacy appears similar to that of the overall United States, based on crude comparisons to the 2003 National Assessment of Adult Literacy (NAAL). The NAAL identified 36% of respondents as having basic or below basic health literacy skills, but the exact method of assessment was different from the NVS. Nonetheless, the overall group of participants in this study may not have been at the high risk of limited health literacy that was expected prior to recruitment.

Some trends between NVS scores and demographic data were seen. Compared to those speaking English at home, low health literacy was more common among those speaking Spanish at home (39% vs. 60%, respectively). The trend is consistent with national data from the 2003 NAAL, which showed that limited health literacy is associated with limited use of the English language (Kutner et al., 2006). However, it is unknown whether the five individuals who spoke Spanish at home would have preferred to take the NVS in Spanish because it was not offered. If these individuals would have scored higher on the Spanish version than the English version, no trend would exist. The small overall sample size and small number of people who spoke Spanish at home may have limited the ability to detect a significant association using bivariate analysis. In addition, language data was not obtained for one participant. A nonsignificant trend toward lower education and lower health literacy was also observed. Again, this trend is consistent with national data from the NAAL (Kutner et al., 2006), but may not have reached significance here due to the small sample size.
Feasibility of the Newest Vital Sign in a Group Setting

The NVS appeared feasible to administer in a group setting based on the time required for administration, requests for clarification or additional instruction, ability to complete the answer sheet, comfort level, and potential threats to validity observed in this study. The NVS took about seven and a half minutes to administer, with a maximum time of about eight and a half minutes in one group. This time appears reasonable, given the average time of 2.9 minutes (range: 1.5-6.2 minutes) for one-on-one administration reported in the literature (Weiss et al., 2005) and the number of people in each of these focus groups. Care was taken to ensure all participants were finished before moving on, so the actual time required could vary based on the group. All requests for clarification or additional instruction were addressed without providing information about the answer that would affect the validity of the results. Across the entire sample, 13% of answers on the answer sheets were left blank, as participants were permitted to do if they did not know the answer. This finding supports the conclusion that participants were not uncomfortable with attempting the task at hand. Comfort level was also assessed subjectively, with the most salient finding being that participants wanted to see answers immediately after taking the assessment. This concern was addressed by giving all participants an answer sheet at the end of the study and explaining why answers could not be provided earlier.

Potential threats to validity should inform future attempts to use and/or validate the NVS in a group setting. Copying could be prevented by re-seating participants in an area with adequate space to spread out, rather than an intimate
table designed for promoting focus group engagement. Paper-and-pencil notetaking and calculations could be limited by using a smaller answer sheet, removing all excess paper from the area, and by making oral and printed instructions more explicit in this regard. Because the NVS was presented as an opportunity to see “how easy or hard it is to understand the information on a food label,” participants could be told that this activity is like picking up a food label in a grocery store and doing some quick calculations in their head. In this study, those who may have copied answers or used aids in calculation could have received higher scores. Thus, the prevalence of limited health literacy in the sample could be somewhat underestimated. Future studies should apply the findings of this feasibility study to validate the NVS for use in group settings.

Focus Groups

Overall Theme of “Emotions”

Focus group results reflected the unexpectedly powerful, overarching theme of “emotions” across all topics discussed. In reference to children’s weight, weight communication, and the BMI letter, parents voiced feelings of concern, guilt, fear, anger/being upset, rationalization, skepticism, and acceptance (Table 13). Participants were concerned about their child’s current or future weight-related health problems; privacy and self-esteem regarding the BMI screening and letter; and the need for health professionals to be sensitive about their child’s weight. Parents also voiced guilt for their role in their child’s weight. Fear was expressed for a child’s reaction to weight-related words. Participants were angry or upset in response to a variety of issues: offensive weight
terminology, a physician’s inappropriate or inadequate response to their child’s weight, the perceived inappropriate role of schools in BMI screening, and the BMI letter giving information they already knew. It is unclear whether anger in the latter case was related to underlying feelings of guilt and being reminded about a child’s weight problem. Descriptions of parents’ feelings of blame and guilt related to their children’s weight are not new; even in conversations with physicians, previous research found that parents may feel their child’s weight is their responsibility alone and something for which they could be blamed (Edmunds, 2005).

Rationalization of children’s weight was also a common response. Parents referred to muscle mass, heredity, national trends, and underlying medical conditions as explanations. Related to this, parents also expressed skepticism about BMI as a valid measure of excess weight. On the other hand, some parents also expressed acceptance. Specific areas of acceptance included preferable weight terms, discussing children’s weight in the context of health, health professionals’ helpful feedback and nutrition advice, and useful information in the BMI letter. In contrast to those who were angry about the school’s role in BMI screening, other parents did accept the policy.

In general, the overarching theme of parents’ emotional reactions to their children’s weight can be compared to individuals’ emotional reactions to being diagnosed with a chronic illness. For example, in semi-structured interviews of 34 primarily low-income, ethnically diverse diabetes patients, patients’ emotional responses to their diagnosis were categorized according to Kübler-Ross’ stages
of grief (Kahn et al., 2012). Participants expressed denial, anger, bargaining, depression, and acceptance in response to diabetes (Kahn et al., 2012). Some similar emotional themes – such as rationalization (related to denial), anger, being upset, and acceptance – were identified among parents in response to discussing their child’s weight and labels for their excess weight in this study. These varied emotions can help inform and explain parents’ reactions to specific weight terminology, patient-provider communications, and the BMI letter.

**Weight Communication**

This study explored the reasons underlying parents’ preferences for specific weight terms that describe children’s excess weight. Ten weight terms recently tested in a national survey of 445 American parents of 2- to 18-year-old children (Puhl et al., 2011) were used in the focus groups. In general, the terms that focus group participants preferred the most (*weight, weight problem, and unhealthy weight*) and preferred the least (*obese, fat, and extremely obese*) were consistent with the previous survey. In the study by Puhl and colleagues, parents rated terms on a five-point scale (1=not at all, 5=very) for their desirability and the degree to which the terms were stigmatizing, blaming, or motivating to lose weight. *Weight* was rated most desirable (mean rating: 3.65, 95% CI: 3.53, 3.77), followed by *unhealthy weight* (3.42, 95% CI: 3.29, 3.56), *high BMI* (3.35, 95% CI:3.21, 3.48), and *weight problem* (3.06, 95% CI: 2.93, 3.19). Likewise, *unhealthy weight, weight problem, and weight* were rated among the four terms considered most motivating. *Chubby* (mean rating: 2.16, 95% CI: 2.04, 2.28), *obese* (2.11, 95% CI:1.98, 2.24), *extremely obese* (1.88, 95% CI: 1.76, 2.01),
and fat (1.78, 95% CI: 1.67, 1.89) were rated most undesirable, and also most stigmatizing and blaming. The consistency of the current study’s results with a larger, national sample lends credence to its conclusions. In addition, parents’ preferences for more neutral words such as BMI rather than overweight or obese were also seen among participants in the EFNEP pilot study (Gustamachio, 2011).

The qualitative findings in the current study expand on the national survey by helping to explain parents’ stated preferences. Parents voiced no criticisms of weight and viewed it as a straightforward, appropriate word that did not offend anyone. Many parents accepted the terms weight problem and unhealthy weight because they could be applied to overweight or underweight and to just a few extra pounds or many, in keeping with the theme of “normalizing.” The preference for unhealthy weight may also reflect participants’ desire to discuss their children’s weight in the context of their health/health problems, which motivated some to seek medical attention and pursue behavior change. In addition, these preferred terms are consistent with previous research that has asked adults to rate terms for describing their own excess weight (Table 14) (Dutton et al., 2010; Wadden & Didie, 2003; Volger et al., 2011).

Among the least preferred terms, parents voiced strongly negative, emotional reactions to obese, fat, and extremely obese. These words were considered insulting and offensive. Although some research has suggested adults may prefer the use of obese or clinically obese as a medical term to describe a condition (Gray et al., 2011; Tailor & Ogden, 2009), no parents in this
study viewed the words in this positive light for their children’s weight. Parents’ stated reasons for disliking obese, fat, and extremely obese were similar to those reported in a recent focus group study of overweight (n=32) and obese (n=18) African American women who had an interest in losing weight. Although that study’s finding was not specific to children, obese was viewed as an insult and was not a word the women used to describe themselves (James, Pobee, Oxidine, Brown, & Joshi, 2012). Given the difficulty parents had in separating their own weight struggles from their children’s—with many discussing their own weight throughout the focus group—it is not surprising that parents would express similar emotions about words to describe their own weight and their child’s weight. It is also noteworthy that the use of obese to describe children has only become widespread within the past decade. During this time, the CDC has shifted from identifying children at or above the 85th percentile on BMI charts as “at risk for overweight” to “overweight”; children at or above the 95th percentile are now classified as “obese” rather than “overweight” (Ogden & Flegal, 2010). The relatively recent cultural change may help explain why parents consider obese to be particularly unacceptable for describing children.

Focus group findings regarding parents’ positive and negative experiences with patient-provider communication characterize desired traits in health care providers. When dealing with children’s weight, parents want providers to use appropriate, sensitive words; provide helpful feedback and support; and address potential medical causes and consequences of their child’s excess weight. In addition, collaboration with the parent and child to explain the problem in
acceptable, understandable language was preferred. The most common reasons for negative experiences were the use of words considered inappropriate and an inadequate response to the parent’s concerns. Thus, physicians should exhibit sensitivity to patients’ communication needs and take parents’ concerns about the child’s weight seriously. In one small study using nine parent interviews, similar issues were identified. Parents wanted primary care physicians to provide information on healthy eating, “flag when the child was becoming overweight,” and tell the child about the problem with their weight in a “gentle” or “tactful” manner (O’Keefe & Coat, 2009). However, this smaller study did not explore specific patient experiences or word choice in depth. Because limited research had addressed this topic, findings from the current study fill an important gap in the research on weight communication between providers, parents, and children.

Response to the BMI Letter

Reactions to the BMI Letter

A prominent initial reaction to the BMI letter among parents was their tendency to question the validity of BMI for measuring excess weight. This reaction is noteworthy given the following sentences contained in the MA BMI letter: “BMI cannot tell the difference between muscle and fat. An athletic child with a lot of muscle may have a high BMI but not be overweight.” Although these sentences may be intended to present the issue of a child’s weight in a sensitive manner to prevent overreaction, the focus group findings prompt the question of whether such wording is counterproductive. Because of parents’ tendency to rationalize children’s excess weight—even among these parents, who were
enrolling their children in an intensive pediatric weight management program—the wording may limit the letter’s potential to motivate change. In contrast, a sample BMI letter for the state of Arkansas contains the following statement: “If a child is overweight, it is usually because the child has too much body fat … Rarely [emphasis added], a child’s BMI may be high because the child is very muscular.” Future research should investigate the optimal presentation of these issues to ensure BMI information is delivered in a manner that is both sensitive and effective.

Another major theme that emerged was parents’ concern about the BMI screening and letter impacting their children’s self-esteem, including weight-related teasing from peers. These concerns were not unfounded. For example, a large cross-sectional study using a self-administered questionnaire immediately following school-based weight screening found that more overweight students (38.1%) reported being uncomfortable with the weight screening than healthy weight students (8.1%) (P<.001) (Kalich et al., 2008). Weight-related teasing does not appear to increase during the two years that follow screening, but this conclusion is based on the results of a single study (Krukowski et al., 2008). Regarding concerns about the impact of the letter itself, many parents said they would consider the letter acceptable if it was mailed to them directly, as is recommended by the MA DPH. The MA law stipulates that a student’s BMI information “be mailed or otherwise directly communicated in writing to the parent or guardian of the student, in accordance with guidelines of the Department.” Previous research supports the consensus that parents prefer results not be
shared with students in schools and that communication be done via mail (Harris & Neal, 2009; Kubik, Story, & Rieland, 2007; Murphy & Polivka, 2007; Stalter, Kaylor, Steinke, & Barker, 2011). However, it was surprising that a number of parents in the current study said their child brought home a BMI letter from school. It is possible that some of these experiences may have occurred before the MA law went into effect, or some school districts may incorrectly consider their practice of sending a letter home with the student to be “direct, confidential notification.” Future research and policy should include a focus on monitoring the delivery of the BMI letter in Massachusetts.

**Confusion about the BMI Letter**

Among parents’ responses to the MA BMI letter, areas of confusion merit discussion. Some participants had trouble interpreting the child’s weight status and/or understanding the concept of BMI. A majority (67%) of parents who expressed confusion about the BMI letter or weight terminology received an NVS score indicating a possibility or high likelihood of limited health literacy. The need for adequate numeracy skills to evaluate a BMI/BMI percentile and to successfully complete the NVS points to an underlying connection. This finding suggests that health literacy may play a role in parents’ understanding of BMI and thus, their response to the BMI letter. Parents who do not correctly interpret a child’s weight status or become frustrated while reading the letter may be less likely to see a physician or change behaviors, which future research should assess.
Some parents had difficulty interpreting the child’s weight status because of problems with the colored bar. First, the letter required that parents locate the child’s percentile and match this percentile with its position on the colored bar. At least one parent mistook the percentile labels for pounds, and others commented that a mark indicating the child’s actual position on the colored bar would be helpful. In a previous study, the use of color-coded BMI charts promoted understanding among parents with low numeracy skills (Oettinger et al., 2009). However, in the context of the MA BMI letter, some parents made the mistake of focusing on the large green portion of the colored bar and concluding that the sample child was at a healthy weight. As one parent said, “[I] think he has a healthy weight because it’s green.” If schools do not print the letters in color, the segments of the colored bar may be hard to discern. One parent who had already received a letter about her child commented, “Oh, I didn’t get it fancy like this,” when she saw the color version used for the focus groups. Thus, the focus group findings may underestimate the extent of confusion occurring among parents who attempt to interpret their child’s weight status from a letter printed in black and white. In a different approach, the sample BMI letter for the state of Arkansas uses a bar with a triangular marker for the child’s weight status category and black-and-white designs, rather than colors, to denote weight categories (Appendix R). The efficacy of various BMI presentation styles in reducing parents’ confusion about their children’s weight status should be a topic of further research.
Strengths and Limitations

Strengths of the Study

This study benefited from several strengths in its quantitative and qualitative methods. The use of readability formulas and the SAM+CAM enhanced the evaluation of the letter and suggested specific areas for improvement. Incorporating measurement of health literacy with a validated, nutrition-related assessment, the Newest Vital Sign, helped to establish a potential role for health literacy in parents’ responses to the BMI letter. The feasibility assessment of the adapted NVS also sets the stage for future testing and validation of the health literacy measure in a group setting.

The incorporation of qualitative methodology allowed this study to help explain previous findings about the lack of efficacy in parent BMI notification. Because focus groups were held before parents began MIGHTY classes, potential changes in parents’ attitudes related to new nutrition education were avoided. In addition, because parents participated in focus groups with other parents beginning the MIGHTY program, they may have been more likely to open up about experiences with their child’s weight, without fear of judgment from participants. Selection of the 10 weight terms from a large, recent study provided a strong research base to which our findings could be compared. This study fills important gaps in weight communication literature, and provides needed qualitative data to evaluate the MA BMI letter and inform future research on BMI notification.
Limitations of the Study

Limitations and potential biases of this study related to the study population and recruitment, readability and health literacy assessments, and focus groups. The study population was made up of a small group of individuals who were motivated to help their child lose weight, as evidenced by enrollment in an intensive pediatric weight management program. Because of this specific group, findings can not necessarily be generalized to all other parents of obese children in Massachusetts. There was also no information collected from parents/caregivers about their own weight status or that of other children in their household. While some parents indicated through their comments that they were obese, the collection of this information was not standardized. As observed throughout the focus groups, participants' prior experience with communicating about their own weight informed reactions and preferences regarding their child’s weight. Thus, it would have been more informative to examine the potential influence of parents' normal-weight or overweight/obese status on their responses. In addition, no income data were collected because it was not done during the EFNEP pilot study, and reporting of race category data was limited (n=20).

The recruitment process was limited by a small study population (n=29). There was also a lack of information about reasons for participation or nonparticipation. It was not known whether individuals with particularly strong views for or against the BMI screening volunteered to participate in this study, but the possibility for such a bias would exist whenever recruiting a convenience
sample. Because the focus groups were not offered in Spanish, some parents
could not participate and others speaking English as a second language may not
have been able to contribute fully to the discussion. Aside from cases where this
language barrier was evident, no additional information could be collected about
parents’ reasons for declining to participate.

The selected readability and health literacy measures for this study also
had some limitations. Readability formulas (which do not assess all factors that
impact comprehension) and the SAM+CAM (which has subjective elements)
have limitations in predicting the extent to which the BMI letter will be “easily
understood” by its intended audience. Additional important factors that affect
readability, such as printing the colored bar in black and white ink, were not
assessed in this study. Further, the full set of the BMI letter and educational
materials from the DPH tested for readability and suitability in this study could be
considered the optimal packet of BMI materials. Some school districts may
choose to use fewer materials or different materials, which could affect parents’
understanding and responses. Finally, the hypothesized reading level chosen for
this study (grade 6) may have provided a somewhat optimistic estimate of the
readability levels of the materials for their intended audience. About 75% of
Americans can read at this level without difficulty, but materials must be at a 3rd-
grade level be easily readable by 90% of Americans.

The measure for assessing participants’ health literacy, the Newest Vital
Sign, was chosen on the basis of its relevance to nutrition, inclusion of numeracy,
and ease of administration. However, its criterion validity, assessed through
correlation with the TOFHLA, is somewhat low ($r=0.59$). This correlation has
been determined for the fully oral version of the NVS. In this study, the NVS was
instead used with a paper based answer sheet, which was assessed for
feasibility but not validated. The original NVS has also been validated in Spanish,
but that option was not available to participants because focus groups were
conducted only in English. Ideally, participants would have been given a choice
of taking the NVS in their preferred language. The sole option of taking the NVS
in English may have affected the distribution of scores. The small sample size
($n=29$) may also have limited the power to detect associations between
demographic variables and health literacy levels where nonsignificant trends
were observed.

Finally, as with any qualitative method, care must be taken in the use of
focus groups to collect data that is unbiased and representative of all
participants’ perspectives. Dissenting opinions must be invited, a welcoming
environment must be maintained, and specific viewpoints must not be
encouraged more than others through verbal or nonverbal feedback. Despite
training and practice, this author was a relatively inexperienced focus group
facilitator, which is a limitation of the study. In addition, more time for the focus
groups may have been useful to discuss the BMI letter’s comprehensibility and
acceptability in greater depth.

**Implications for Research and Practice**

The results of readability analysis, health literacy assessment, and
qualitative analysis suggest important implications for both research and practice.
In particular, results from this study can be applied to public health and clinical practice regarding the use of readability formulas, measurement of health literacy, patient-provider communication, and recommendations for the BMI letter. Future research designs and priorities can also be informed by the results of this study.

**Implications for Public Health and Clinical Practice**

**Use of Readability Formulas**

The variation in readability results observed in this study suggests the utility of measuring educational materials with more than one readability formula. More than one formula is particularly useful if the Flesch-Kincaid or Flesch Reading Ease formulas are used, as research indicates that these tend to yield lower reading grade-level estimates. Thus, relying on a quick Flesch-Kincaid and Flesch Reading Ease assessment by using Microsoft Word could give individuals in public health an overly optimistic estimate for their materials. Although readability estimates are useful to provide some basic information about the difficulty of written materials, the SAM+CAM can provide additional information about appropriateness for a target audience and suggest specific areas where revision is needed. As seen in the study, even the combination of multiple readability formulas and the SAM+CAM cannot identify all areas that may be potentially problematic for reader understanding. Whenever possible, usability testing with members of the intended audience is preferred.
Measurement of Health Literacy

In this study, health literacy levels were not significantly associated with education levels or gender, language, or ethnicity. These findings reinforce the concept that health educators and clinicians cannot reliably predict which audiences or patients will have limited health literacy skills. Instead, professionals should use a health literacy measure such as the NVS to screen patients or employ a universal precautions approach. A universal precautions approach promotes understanding for all individuals by using clear communication techniques such as “teach back” – asking patients to repeat oral instructions or information in their own words. Additional precautions can be taken to improve written communication, self-management, and support systems (DeWalt et al., 2010).

Patient-Provider Communication

This study described a variety of positive and negative reactions that participants experienced when communicating with health professionals about their child’s weight. These responses can inform recommendations for health professionals seeking to engage parents in a discussion about their child’s weight to promote positive behavior change. In general, conversations that focus on the health aspects of excess weight are likely to be most motivating. Providers should offer support, provide specific feedback about recommended behaviors, and make referrals to specialists and/or registered dietitians when appropriate. Perhaps most importantly, health professionals should recognize the potential for parents to view the medical term obese as offensive and insulting. Avoiding the
use of such language could avert parents’ negative emotional reactions to weight conversations and allow for a more productive exchange. The results of this study and previous research (Puhl et al., 2011) suggest that discussions about changes in weight, a weight problem, or an unhealthy weight will be more acceptable and respectful to many parents.

**Recommendations for the BMI Letter**

One specific aim of this study was to identify ways the BMI letter could be made more effective and respectful (Specific Aim 4d). Results from the readability formulas, SAM+CAM, and focus groups all have implications for the efficacy of the BMI letter. As discussed previously, the readability formulas suggest the physical activity and frequently asked questions educational materials could benefit from clearer language. The SAM+CAM also points to specific content areas of improvement for each material. The focus groups provided a rich source of data on parents’ reactions to and understanding of the BMI letter. These results have implications for improving the format, delivery, and content of the MA BMI letter. Because the current study was small and the sample was not representative of the entire state, significant changes to the BMI communication process should be pre-tested with more members of the intended audience.

To improve the format of the letter, marking the child’s position directly on the colored bar should be considered. In addition, redesigning the colored bar for black-and-white printing could enhance legibility. As indicated by overwhelming consensus among parents and mandated in the law, the BMI letter should be
delivered directly to parents by mail and not given to students in school. The MA DPH should allocate resources to implement and monitor that direct delivery of the letter is occurring, which should improve parents’ acceptance of the BMI screening policy. To enhance the delivery process, training should be provided for relevant health care professionals and educators (physicians, nurses, school nurses, teachers, etc.) to ensure these professionals are adequately equipped to respond to concerned families who have received the letter. Families must be directed to resources for longer-term management and follow up, such as pediatric weight management services and university extension nutrition programs.

The content of the BMI letter should be easily understood and communicate an effective message. The SAM+CAM results suggest potential areas for improvement in the letter’s comprehensibility; at a minimum, the text should explain or clarify the concepts of BMI, percentile, and screening. Emergent themes from focus groups could also be applied to enhance the messages the BMI letter delivers. Using familiar values in message design is considered a form of persuasion (Helitzer et al., 2009). Thus, the BMI letter could include a greater focus on potential weight-related health problems, which is in line with the theme of parents’ concern for their children’s health. The letter could also acknowledge the variety of emotions parents may experience in response to the information. Many parents’ negative emotional reactions were related to concern for their children’s self-esteem, which suggests that a focus on promoting health and healthy behaviors may be preferable to a focus on weight.
Although children’s weight is easy to measure, the ultimate goal of the screening program is to promote children’s health. Because questioning the validity of BMI emerged as a strong theme, the wording of the BMI and muscle sentences should be re-examined. Finally, the letter could incorporate preferred language, such as *weight problem* and/or *unhealthy weight*, to enhance acceptance among parents.

**Implications for Future Research**

This study began to fill some gaps in the literature regarding readability and health literacy, weight communication, and BMI screening and notification. The findings can also inform new approaches to related research where warranted. Future research that assesses health education materials should not be limited to the use of readability formulas. The SAM+CAM, a new, expanded version of the SAM, can be incorporated into future studies to improve the assessment of educational materials. As previously discussed, readability formulas are limited by a reliance on word length and sentence length, whereas the SAM+CAM can pinpoint specific revisions to both content and format that should enhance reader understanding.

For future research in health literacy, this study has demonstrated that administering the NVS in a group setting is feasible and can be done in less than 10 minutes. Future studies in nutrition should aim to validate and employ this time-saving approach. Its greater use in research would help to broaden understanding of how health literacy impacts nutrition outcomes. Use of the NVS can also help to identify individuals who may experience confusion when
interpreting health education materials, as seen with the BMI letter in this study. Thus, an additional application of the NVS for future nutrition research lies in identifying target populations for usability testing and evaluation of specific health promotion materials and interventions. The distribution of NVS scores in this study suggested a role for health literacy in BMI communication, which can provide the basis for a quantitative, cross-sectional study investigating this relationship in more depth.

In the current study, the unexpected theme of “emotions” emerged with respect to weight communication and BMI notification. A variety of emotions that may affect parents’ responses to communicating about their child’s weight and receiving the BMI letter were identified. This role of emotions in shaping responses to the BMI letter should be considered in more depth in future qualitative research. In addition, the role of a child’s age or life stage (e.g., adolescents versus younger children) should be examined, as parents’ preferences for words used to describe their child’s weight may vary with age. The findings of this study can also inform quantitative research on parents’ reactions to the MA BMI letter, their understanding of it, and actions they have taken or plan to take. Future quantitative research should also explore actions that pediatricians take in response to visits with parents and children who have received the MA BMI letter.

In general, research on health literacy in nutrition, weight communication, and approaches to BMI notification have been cross-sectional in nature. New studies should examine interventions in these areas using prospective or
experimental designs where appropriate. Future research on BMI notification should also examine the efficacy of the BMI letter in the context of other local and national policies and programs that affect childhood obesity, such as local food environments and access to healthful foods. Given this broader context, it is important to consider the extent to which a single communication strategy will impact health outcomes.
CHAPTER 11
CONCLUSIONS

Since 2010, all public schools in Massachusetts have been required to perform BMI screening for students in grades 1, 4, 7 and 10 and to notify parents of the results (MA DPH, 2010). Despite the widespread adoption of BMI screening and notification as a childhood obesity prevention strategy, research on the effectiveness of this public health practice is limited. In addition, health literacy has not been considered in research on BMI screening and notification. The purpose of the current study was to conduct a qualitative evaluation of parents’ responses to the Massachusetts BMI letter in the context of the letter’s readability and participants’ health literacy levels. Readability estimates for the BMI letter and some educational materials were largely above preferred sixth-grade levels. The readability findings were of particular concern given the results of the Newest Vital Sign, which indicated 41% of parents had a possibility or high likelihood of limited health literacy. Measuring health literacy with the NVS in this group setting was deemed feasible. Parents clearly identified weight terms used for children that were most preferred (weight, weight problem, and unhealthy weight) and least preferred (obese, fat, and extremely obese). Parents’ responses to the BMI letter were mixed, and areas of confusion were identified. An overall theme of “emotions” emerged to describe how parents reacted to issues of children’s weight, weight language, and the MA BMI letter. This study’s findings had implications for improving the format, delivery, and content of the MA BMI letter, and relevant recommendations were made. Future research
should further examine the roles of parents’ emotional responses and health literacy skills in their interpretation and acceptance of the MA BMI letter. The results of this research can inform an approach to respectfully and effectively communicate BMI results to parents in Massachusetts and nationwide.
<table>
<thead>
<tr>
<th>Name</th>
<th>Abbreviation</th>
<th>Variables Measured</th>
<th>Time Needed</th>
<th>Psychometrics</th>
<th>Language</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Term Recognition Test</td>
<td>METER</td>
<td>Word recognition, reading</td>
<td>About 2 min.</td>
<td>Validity: REALM (r=0.74)</td>
<td>English</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Reliability: Cronbach’s α=0.93</td>
<td></td>
</tr>
<tr>
<td>Medical Terminology Achievement Reading Test</td>
<td>MART</td>
<td>Word recognition, reading</td>
<td>3-5 min.</td>
<td>Validity: WRAT (Cronbach’s α=0.98)</td>
<td>English</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Reliability: N/A</td>
<td></td>
</tr>
<tr>
<td>Newest Vital Sign</td>
<td>NVS</td>
<td>Reading, reasoning, numeracy</td>
<td>About 3 min.</td>
<td>Validity: English: TOFHLA (r=0.59), Spanish: TOFHLA-S (r=0.49)</td>
<td>English, Spanish</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Reliability: English: Cronbach’s α=0.76, Spanish: Cronbach’s α=0.69</td>
<td></td>
</tr>
<tr>
<td>Nutritional Literacy Scale</td>
<td>NLS</td>
<td>Reading, comprehension, nutrition literacy</td>
<td>Untimed</td>
<td>Validity: S-TOFHLA (r=0.61)</td>
<td>English</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Reliability: Cronbach’s α=0.84</td>
<td></td>
</tr>
<tr>
<td>Rapid Estimate of Adult Literacy in Medicine</td>
<td>REALM</td>
<td>Word recognition, reading</td>
<td>3-5 min.</td>
<td>Validity: Peabody Individual Achievement Test-Revised (PIAT-R) (r=0.98), Slosson Oral Reading Test-Revised (SORT-R) (r=0.96)</td>
<td>English</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Reliability: Test-retest=0.98</td>
<td></td>
</tr>
<tr>
<td>Shortened REALM</td>
<td></td>
<td>Word recognition, reading</td>
<td>1-2 min.</td>
<td>Validity: Reading recognition section of PIAT-R (r=0.97), Wide Range Achievement Test-Revised (WRAT-R) (r=0.98), Slosson Oral Reading Test-Revised (SORT-R) (r=0.96)</td>
<td>English</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Reliability: Test-retest=0.99</td>
<td></td>
</tr>
<tr>
<td>REALM-Revised</td>
<td>REALM-R</td>
<td>Word recognition, reading</td>
<td>1-2 min.</td>
<td>Validity: WRAT-R (r=0.64)</td>
<td>English</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Reliability: Cronbach’s α=0.91</td>
<td></td>
</tr>
<tr>
<td>Short Assessment of Health Literacy in Spanish</td>
<td>SAHLSA</td>
<td>Word recognition, reading, comprehension</td>
<td>3-6 min.</td>
<td>Validity: TOFHLA-S (r=0.65)</td>
<td>Spanish</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Reliability: Cronbach’s α=0.92, Test-retest=0.86</td>
<td></td>
</tr>
<tr>
<td>Short Assessment of Health Literacy in Spanish and English</td>
<td>SAHL—S&amp;E</td>
<td>Word recognition, reading, comprehension</td>
<td>2-3 min.</td>
<td>Validity: Spanish: SAHLSA (r=0.88), TOFHLA-S (r=0.62)</td>
<td>English, Spanish</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>English: REALM (r=0.94), English TOFHLA (r=0.68)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Reliability: Spanish: Cronbach’s α=0.80, English: Cronbach’s α=0.89</td>
<td></td>
</tr>
<tr>
<td>Test of Functional Health Literacy in Adults</td>
<td>TOFHLA, TOFHLA-S (Spanish)</td>
<td>Reading, comprehension, numeracy (Some omit numeracy section)</td>
<td>22 min. (Timed reading and numeracy)</td>
<td>Validity: English: WRAT-R (r=0.74), REALM (r=0.84), Spanish: N/A</td>
<td>English, Spanish</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Reliability: English: Cronbach’s α=0.98, Test-retest=0.92, Spanish: Cronbach’s α=0.98, Test-retest=0.84</td>
<td></td>
</tr>
<tr>
<td>Brief/Short TOFHLA</td>
<td>S-TOFHLA</td>
<td>Reading, comprehension, numeracy (Some omit numeracy section)</td>
<td>Timed reading (7 min.), numeracy (5 min.)</td>
<td>Validity: English only, Numeracy: REALM (r=0.61), Reading: REALM (r=0.81)</td>
<td>English, Spanish</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Reliability: English only, Numeracy: Cronbach’s alpha=0.68, Reading: Cronbach’s alpha=0.97</td>
<td></td>
</tr>
</tbody>
</table>

Sources: Baker et al., 1999; Bass et al., 2003; Davis et al., 1991, 1993; Diamond, 2007; Hanson-Divers, 1997; Lee et al., 2006, 2010; Mancuso, 2009; Parker et al., 1995; Rawson et al., 2009; Weiss et al., 2005
Table 2. Selected Readability Measures

<table>
<thead>
<tr>
<th>Readability Measure</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flesch Reading Ease Scale</td>
<td>The Flesch Reading Ease Scale is based on average sentence length and average number of syllables per word. The formula generates a number from 0 to 100, with higher numbers for text that is easier to read.</td>
</tr>
<tr>
<td>Flesch-Kincaid Reading Grade Level</td>
<td>The Flesch-Kincaid Reading Grade Level modifies the Flesch Reading Ease Scale to generate a grade level estimate. For example, a score of 8.2 indicates an average eighth-grade student would understand the text.</td>
</tr>
<tr>
<td>Gunning Frequency of Gobbledygook (FOG) Index</td>
<td>The Gunning FOG Index is based on the average sentence length and percentage of polysyllabic words. It generates a number that corresponds to a grade level estimate, similar to the Flesch-Kincaid formula.</td>
</tr>
<tr>
<td>Simplified Measure of Gobbledygook (SMOG)</td>
<td>Calculation of the SMOG is based on the number of polysyllabic words per 30 sentences. The reading grade level calculated from SMOG indicates a level at which 100% of readers can understand the text. Thus, SMOG readability estimates are typically higher than other formulas.</td>
</tr>
<tr>
<td>Fry Readability Graph</td>
<td>Reading level is determined from the intersection of the number of sentences and syllables per 100 words when plotted on a graph.</td>
</tr>
</tbody>
</table>

Sources: Carbone & Zoellner, 2012; Flesch, 1948; Fry, 1968; Gunning, 1952; Kincaid et al., 1975; McLaughlin, 1969
<table>
<thead>
<tr>
<th>Table 3. Demographic Characteristics of Participants</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>24</td>
<td>82.8</td>
</tr>
<tr>
<td>Male</td>
<td>5</td>
<td>17.2</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-29</td>
<td>3</td>
<td>10.3</td>
</tr>
<tr>
<td>30-39</td>
<td>12</td>
<td>41.4</td>
</tr>
<tr>
<td>40-49</td>
<td>9</td>
<td>31.0</td>
</tr>
<tr>
<td>50-59</td>
<td>4</td>
<td>13.8</td>
</tr>
<tr>
<td>&gt;60</td>
<td>1</td>
<td>3.4</td>
</tr>
<tr>
<td><strong>Number of Children</strong> (through age 19)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 children</td>
<td>1</td>
<td>3.7</td>
</tr>
<tr>
<td>1 child</td>
<td>10</td>
<td>37.0</td>
</tr>
<tr>
<td>2 children</td>
<td>5</td>
<td>18.5</td>
</tr>
<tr>
<td>3 children</td>
<td>8</td>
<td>29.6</td>
</tr>
<tr>
<td>4-6 children</td>
<td>3</td>
<td>11.1</td>
</tr>
<tr>
<td><strong>Ages of Children</strong> (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;1-5</td>
<td>5</td>
<td>8.5</td>
</tr>
<tr>
<td>6-10</td>
<td>18</td>
<td>30.5</td>
</tr>
<tr>
<td>11-15</td>
<td>31</td>
<td>52.5</td>
</tr>
<tr>
<td>16-18</td>
<td>5</td>
<td>8.5</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>17</td>
<td>58.6</td>
</tr>
<tr>
<td>Non-Hispanic/Latino</td>
<td>9</td>
<td>31.0</td>
</tr>
<tr>
<td>Did Not Respond</td>
<td>3</td>
<td>10.3</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>American Indian or Alaskan Native</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Asian</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Black or African American</td>
<td>10</td>
<td>33.3</td>
</tr>
<tr>
<td>Native Hawaiian or Other Pacific Islander</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>White</td>
<td>11</td>
<td>36.7</td>
</tr>
<tr>
<td>Did Not Respond</td>
<td>9</td>
<td>30.0</td>
</tr>
<tr>
<td><strong>Education Level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some High School</td>
<td>5</td>
<td>17.2</td>
</tr>
<tr>
<td>High School Graduate/GED</td>
<td>11</td>
<td>37.9</td>
</tr>
<tr>
<td>Some College/Associate’s</td>
<td>10</td>
<td>34.5</td>
</tr>
<tr>
<td>Bachelor’s Degree</td>
<td>3</td>
<td>10.3</td>
</tr>
<tr>
<td><strong>Language Spoken</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>23</td>
<td>79.3</td>
</tr>
<tr>
<td>Spanish</td>
<td>5</td>
<td>17.2</td>
</tr>
<tr>
<td>Did Not Respond</td>
<td>1</td>
<td>3.4</td>
</tr>
</tbody>
</table>

*Two participants provided a number of children that was not consistent with the number of ages listed and were omitted from the data shown here.

*bOne participant self-identified as Black/African American and White. All other participants selected only one category or did not answer.
Table 4. SAM+CAM and Readability of BMI Letter and Educational Materials

<table>
<thead>
<tr>
<th></th>
<th>Letter</th>
<th>“Eat Healthy”</th>
<th>“Right Amount”</th>
<th>“Be Active”</th>
<th>BMI FAQs</th>
</tr>
</thead>
<tbody>
<tr>
<td>SAM+CAM (%)a</td>
<td>60</td>
<td>62</td>
<td>66</td>
<td>62</td>
<td>48</td>
</tr>
<tr>
<td>Fry</td>
<td>7</td>
<td>4</td>
<td>3</td>
<td>8/9</td>
<td>10</td>
</tr>
<tr>
<td>FOG</td>
<td>7.5</td>
<td>5.8</td>
<td>6</td>
<td>9.2</td>
<td>10.1</td>
</tr>
<tr>
<td>SMOG</td>
<td>7</td>
<td>7</td>
<td>6</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>Flesch Reading Easeb (Grade level)</td>
<td>84.5 (6)</td>
<td>91.1 (5)</td>
<td>94.6 (5)</td>
<td>69.7 (8-9)</td>
<td>71.9 (7)</td>
</tr>
<tr>
<td>Flesch-Kincaid</td>
<td>5.1</td>
<td>2.9</td>
<td>2.9</td>
<td>6.8</td>
<td>7.5</td>
</tr>
</tbody>
</table>

aAll SAM+CAM scores fall within the range of adequate (>70%=superior, 40-69%=adequate, 0-39%=not suitable)
bScore classification and estimated reading grade level: 90-100=very easy (fifth grade), 80-90=easy (eighth grade), 70-80=fairly easy (seventh grade), 60-70=standard (eighth-ninth grade)

Table 5. Newest Vital Sign Categories and Scores

<table>
<thead>
<tr>
<th>Category</th>
<th>Score</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Likelihood (50% or more) of Limited Literacy (Score = 0-1)</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>5</td>
<td>17.2</td>
</tr>
<tr>
<td>Possibility of Limited Literacy (Score = 2-3)</td>
<td>2</td>
<td>5</td>
<td>17.2</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>2</td>
<td>6.9</td>
</tr>
<tr>
<td>Adequate Literacy (Score = 4-6)</td>
<td>4</td>
<td>9</td>
<td>31.0</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>3</td>
<td>10.3</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>5</td>
<td>17.2</td>
</tr>
</tbody>
</table>
**Table 6. Parents’ Reactions to 10 Words Describing Children’s Excess Weight**

<table>
<thead>
<tr>
<th>Reaction</th>
<th>Weight Word</th>
<th>Selected Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Most Preferred</strong></td>
<td>Weight problem</td>
<td>I’d be open to the discussion. I’d be open to the discussion. That’s not bad, I don’t see that as a bad word … We use weight, just check your weight today and how much you weigh.</td>
</tr>
<tr>
<td></td>
<td>Unhealthy weight</td>
<td>Well, weight problem, I don’t see it as bad as the other words. Weight problem could be just a few pounds or it could be a hundred pounds so I don’t see it as offensive – no. That word is OK … because a weight problem could be either low weight or high weight.</td>
</tr>
<tr>
<td><strong>Mixed Reactions</strong></td>
<td>High BMI</td>
<td>It’s not an offensive word. It’s telling you the truth, just straightforward – unhealthy. [That’s OK] with an explanation … But it is better than most of those other words.</td>
</tr>
<tr>
<td></td>
<td>Overweight</td>
<td>That’s just letting you know that your kid’s above weight, but they don’t really understand what that means, so I don’t think that’s bad. If a child is overweight then they’re going to see that number as something very bad … it could bring a child to having a very bad self-image because of that.</td>
</tr>
<tr>
<td><strong>Not Applicable Reactions</strong></td>
<td>Heavy</td>
<td>That’s just letting you know that your kid’s above weight, but they don’t really understand what that means, so I don’t think that’s bad. I think that’s so, like, obscure, it’s just not – because heavy could be a bag of rice. I think it refers more to an object, like this is heavy. It shouldn’t be used for a person.</td>
</tr>
<tr>
<td></td>
<td>Chubby</td>
<td>That’s not a good word. I would rather hear that than hear the doctor say my son is obese or severely obese. I would rather see overweight. That’s an alright word I would say.</td>
</tr>
<tr>
<td></td>
<td>Obese</td>
<td>It used to be a cute word. When they get older something happens. They’re like, don’t call me that.</td>
</tr>
<tr>
<td></td>
<td>Fat</td>
<td>Nasty. I hate that word, I do. That’s mean. Very offensive.</td>
</tr>
<tr>
<td><strong>Least Preferred</strong></td>
<td>Extremely obese</td>
<td>Extremely offensive. That’s scary, yeah, that’s scary. That’s, ohhh, that is brutal.</td>
</tr>
</tbody>
</table>
Table 7. The Variety of Reactions to Obese for Describing Children’s Excess Weight

<table>
<thead>
<tr>
<th>Theme</th>
<th>Selected Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>NEGATIVE REACTIONS TO OBESE</strong></td>
<td></td>
</tr>
<tr>
<td>Surprise</td>
<td><em>When I took [my son] to his physical and the pediatrician suggested to me, “I'm going to refer him to the obesity clinic,” it was like an eye opener … Is he really that fat?</em></td>
</tr>
<tr>
<td>Offense</td>
<td><em>That word needs to either be broken down or it needs to be taken off everything that they have in the doctor’s [office] and try to put a positive word in there. I don't like it at all, that’s very offensive.</em></td>
</tr>
<tr>
<td>Disgust</td>
<td><em>I hate that word.</em></td>
</tr>
<tr>
<td></td>
<td><em>Nasty.</em></td>
</tr>
<tr>
<td>Rejection</td>
<td><em>I see obese as where someone is huge, and I don't think they should use that word for kids.</em></td>
</tr>
<tr>
<td></td>
<td><em>It bothers me, and especially with a kid, because they don't understand it as much, and if you’re looking at a chart, and a kid sees an obese person, they don’t see themselves like that.</em></td>
</tr>
<tr>
<td>Concern</td>
<td><em>If [the doctor] says that he’s obese, I'd be concerned and worry, try to find what the solution is.</em></td>
</tr>
<tr>
<td><strong>POSITIVE REACTIONS TO OBESE</strong></td>
<td></td>
</tr>
<tr>
<td>Acceptance</td>
<td><em>It depends on how they use it, but I don't see a problem with it.</em></td>
</tr>
<tr>
<td>Motivation</td>
<td><em>I wouldn't feel bad about that [word]. It would just let me know that I need to change something in my child.</em></td>
</tr>
</tbody>
</table>
Table 8. Positive and Negative Experiences with Health Professionals

<table>
<thead>
<tr>
<th>Theme</th>
<th>Selected Quotes</th>
</tr>
</thead>
</table>
| **Appropriate words used**           | My daughter’s pediatrician, they use weight as a word, not obesity or fat, you know, weight, having weight issues and made her feel like a bigger part, saying that a majority of kids these days have weight issues: lower or higher.  
They just said my daughter was gaining X amount of weight … They didn’t say anything negative. They just said that they took her weight from previous years and then added it up to the next physical year.  
She basically talked about it, the weight and the BMI of my daughter, that she needs to do more exercise … and that was basically it. None of it was offensive. |
| **Helpful feedback and support**     | I don’t think I ever had any negative, any kind of feedback is good feedback … just telling what kinds of foods to eat, the portion size, how often to eat, what time not to eat at.  
My son ended up losing some weight and the doctor gave him a pat on the back. He said good and good job Mom.  
It’s been very educational for myself, stuff that I didn’t know before, more detail about it. I learn more about it every day, so it’s a good experience, really good experience. I don’t have any complaints about it. |
| **Addressed medical causes, consequences** | I’ve had a good experience … they’ve been so polite with her … giving hope to her that she can lose weight and feel the way that she wants … for my granddaughter, that wasn’t only what we were eating, was the new medication that she was taking increased her appetite and she gained weight, a lot of weight.  
When I brought my concern about my daughter, yeah, she was supportive about it … I asked her if my daughter could be referred to any particular doctor, and she didn’t hesitate to do that.  
[The doctor] figured out all the ideas for me, which was awesome. She sent her to get a blood test and her sugar levels, they were too high. So it’s a good thing she do that because the spots in her neck, she said it’s not eczema, it’s a sign of diabetes, so that was awesome. I was so excited that she really figured that out. |
| **Visits with nutritionists**        | They spoke to my daughter and they said, you know what, when you eat, when you have a piece of chicken, try not to eat another piece. Try to fill up on fruits and vegetables. That’s what I try to get my kids to do, that’s a positive thing. And don’t skip meals, that was one too.  
When we saw the nutritionist, the nutritionist was very wonderful. She reviewed everything. She didn’t speak to me, she spoke to my son, and I did appreciate that because he is the patient … She goes … let’s try to work on how we can help make you become healthier. |

– Continued on next page –
## NEGATIVE EXPERIENCES

<table>
<thead>
<tr>
<th>Theme</th>
<th>Selected Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inappropriate words used</td>
<td>The word that I don’t like – it was used for me, but also for my kid – obese. I don’t like that word, I really don’t like that word. They weighed [my child] and then the doctor told him, ‘Oh, for your age you’re fat.’ ... [The doctor was like] that’s my way of making him understand that he needs to lose weight.</td>
</tr>
<tr>
<td>Inadequate response to weight concerns</td>
<td>I had a concern with my son’s previous pediatrician that I had concerns about my son’s weight, and he said he’ll grow out of it, he’ll grow out of it – until recently, a couple of years ago, we changed the pediatrician and the first thing this new pediatrician said to us was the weight issue ... I was angry at the first pediatrician because I could have nipped this in the bud years ago. The only time [my daughter’s pediatrician] talks about [weight] is on her physical when she shows me the growth on charts, compares age and weight, the BMIs and all that. That’s the only time we talk about it. It concerned me that if I didn’t say anything nothing like this would happen.</td>
</tr>
</tbody>
</table>
### Table 9. Initial Reactions to the BMI Letter

<table>
<thead>
<tr>
<th>Theme</th>
<th>Selected Quotes</th>
</tr>
</thead>
</table>
| **New information was not being communicated** | Yeah, I mean I would look at it, but it’s not telling me anything that I probably don’t already know.  
I’ve gotten something like this … I was kind of upset ’cause I said, ‘Who are these people?’ I take my kids to the doctor so I already know where they stand.  
I don’t see the point of them sending this really because if you bring your kids to the doctor regularly then they should be doing a printout as of what is going on with your child to you and they should be discussing it. |
| **The letter was acceptable/helpful**      | It’s actually good that they do it because you get to see – back when you’re younger they never did this so – you just get to see where they compare and where they should be.  
[The letter] only encouraged me to move … I didn’t have a problem with it … it only helps me.  
I did get mine in the mail, so I thought it was very helpful … Health-wise a kid can don’t even know he has health problems and end up having a heart attack or something just ’cause he’s overweight … so I don’t have no problems with it. |
| **Validity of BMI was questionable**       | • Because BMI doesn’t measure muscle  
Because a kid with muscle is not obese … I got kids, basketball, football, soccer, and they go to the gym, they lift weights, they run. When they lifting those weights that’s where the muscle comes in – they’ll be thicker, but that’s all muscle right there.  
The one thing that I do like about this letter is that it does say that BMI cannot tell the difference between muscle and fat.  
• Because BMI only considers height and weight  
They’re not doing the water test, they’re not doing the pinching and all that. They’re just doing it by their formula weight – height – here’s your index, you know?  
It seems like you’re profiling him because it seems like, let’s line up five kids, and they’re all the same height, but not all the same weight, not all the same build. It depends – some have taller torso, some have smaller torsos, longer legs – whatever. Where do they come up with this stuff?  
• Because BMI was inconsistent with their own evaluations  
I had some friends come to me and tell me, ‘Do you believe the doctor said my child is overweight?’ and their kid’s next to mine … they’re crazy, they’re not overweight. |
### Table 10. Mixed Reactions to BMI Screening in Schools

<table>
<thead>
<tr>
<th>Theme</th>
<th>Selected Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>POSITIVE REACTIONS</strong></td>
<td></td>
</tr>
</tbody>
</table>
| **Screening could be helpful and motivating** | *I understand why they do it. It’s actually good that they do it because you get to see – back when you’re younger they never did this so – you just get to see where they compare and where they should be.*  
*This is very positive, and I think everybody should get it and get screened … I’m just glad the school noticed and they’re out there to help the kids with their weight.*  
*I seen that they do that in school for the kids, and my granddaughter has always been over what they are looking for. And that’s new because when I was in school and my kids were in school, they never did that. So I’m kind of glad that they do because that’s how I got into this [pediatric weight management] program.* |
| **NEGATIVE REACTIONS**                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| **Screening should not be part of the school’s role** | *This should not be coming from the school system, but I do understand some school systems are doing it because not everybody constantly goes to their physicians. However, it should be something like, if you don’t see a physician … it really should be coming from a physician and not a nurse from a school.*  
*The school shouldn’t have to send you a letter about what’s going on with your kid because the kid lives with you, and they’re just a school nurse, because I don’t trust a school nurse. I don’t let them give shots to my kids – nothing. I will go to the doctor if anything needs to happen.* |
| **Screening could impact the child’s self-esteem** | *The school nurses do … their little check-ups that they do in school, but they do them in groups. They could probably have a little better one-on-one situation instead of making another kid feel bad next to another kid.* |
| **The letter could impact the child’s self-esteem** | *When my son showed [the letter] to me – Mom, I’m not this way am I? – it already started the situation.*  
*I mean I’m OK with the letter, depending on I’m the only person that sees this letter … Kids are cruel and when you’re getting up to the kids that are in the fourth, fifth grade they’re smart, and if they know what this is and it’s being circulated around then there’s a problem.*  
*When we get those BMIs from the school … I don’t like the fact that my son gets to see that before I can look at it … they don’t send it home in an envelope. They send it home just as a piece of paper as is – my son can look at that.* |
Table 11. Parents’ Understanding of the BMI Letter

<table>
<thead>
<tr>
<th>AREAS OF UNDERSTANDING</th>
<th>Selected Quotes</th>
</tr>
</thead>
</table>
| The request to seek medical attention | To see your son’s pediatrician to hopefully get on the right track to get your son healthy or your child.  
 Basically see your doctor and see what you can do about it, what options your child has. |

<table>
<thead>
<tr>
<th>AREAS OF CONFUSION</th>
<th>Selected Quotes</th>
</tr>
</thead>
</table>
| Interpreting the child’s weight status | I have to read it a couple times before I actually knew how to understand the graph, even though it’s a simple graph, but I have to read it a couple times … Be more forward to it: Your son falls right here.  
 The green is healthy weight? But down here they question it as overweight. I think this child is fine.  
 Think he has a healthy weight because it’s green.  
 It tells me that after 85 pounds and his height is going to be overweight and obviously after 95 pounds he’s going to be obese or a percentage higher than that so my reaction to that is that there is definitely something wrong.  
 [The colored bar shows that] it’s a small percentage of kids that are either underweight or overweight. |
| Interpreting BMI | High body mass and it says index so how would I explain that. I would ask her what does that mean? What’s high body mass? Mass means big right? Index is? I don’t know what index is so I don’t understand that.  
 I’ve had that in my weight scale, but I really don’t know much of it either. |
Table 12. Barriers to Making Changes

<table>
<thead>
<tr>
<th>Themes</th>
<th>Selected Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of control over food outside the home</td>
<td>I think I would also like to see this be a look at the school itself too because I know my son comes home with candy from his teachers … If they want us to be healthier with him at home I think there needs to be a look at the lunches in school.</td>
</tr>
<tr>
<td>Cost/availability of safe physical activity</td>
<td>A lot of people, they don’t know what is offered for the kids. Like at my son’s school, they don’t have any after-school activities, all they have is arts. What the kid is going to be doing? Sitting down and just drawing. I think for me we need to run, walk, eating more good, healthy, active, but when I move here I live in a house with a yard, he play every day, we walk – but when I move here, in Springfield, for me it’s scary going somewhere. Something is not good here, somebody’s smoking, and I don’t want my child to see that. Like too much money to get your child into the activity, it’s really expensive.</td>
</tr>
<tr>
<td>Cost of physician visit</td>
<td>Not a lot of people out there do have health insurance. [The letter] could suggest like changing the kid’s diet because doctors are about money, you gotta pay co-pay … include some suggestions where you don’t gotta spend that money.</td>
</tr>
<tr>
<td>Lack of time or Internet access to seek information</td>
<td>I guess some information from, it says you can go to the website, maybe they could include the information because everybody doesn’t have Internet access. I … don’t have time to spend on a computer all night I mean looking for information. If you believe that there’s something wrong with him then I think we should speak on the phone.</td>
</tr>
<tr>
<td>Emotion</td>
<td>Context</td>
</tr>
<tr>
<td>------------------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Concern</td>
<td>A child’s current or future health problems related to weight</td>
</tr>
<tr>
<td></td>
<td>A child’s privacy and self-esteem regarding the BMI screening</td>
</tr>
<tr>
<td></td>
<td>and the contents of the BMI letter</td>
</tr>
<tr>
<td></td>
<td>The need for health professionals to be sensitive about a child’s weight</td>
</tr>
<tr>
<td>Guilt</td>
<td>Parents’ role in their child’s weight</td>
</tr>
<tr>
<td>Fear</td>
<td>A child’s reaction to weight words or communication with health professionals</td>
</tr>
<tr>
<td></td>
<td>Words describing children’s excess weight (unhealthy weight, extremely obese)</td>
</tr>
<tr>
<td>Offensive weight terms (obese, fat, extremely obese)</td>
<td>I hate [the word obese], I do. [The word fat] is horrible. [Extremely obese is] extremely offensive.</td>
</tr>
<tr>
<td>---------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Physician’s inadequate response to a child’s weight</td>
<td>I had a concern with my son’s previous pediatrician that had concerns about my son’s weight, and he said he’ll grow out of it … the first thing this new pediatrician said to us was the weight issue … I was angry at the first pediatrician because I could have nipped this in the bud years ago. The only time [my daughter’s pediatrician] talks about [weight] is on her physical when she shows me the growth on charts, compares age and weight, the BMIs and all that.</td>
</tr>
<tr>
<td>Physician’s inappropriate response to a child’s weight</td>
<td>They weighed [my child] and then the doctor told him, ‘Oh, for your age you’re fat.’ And then we all looked at the doctor – like whoa, I don’t think you’re supposed to be talking to him like that and then the kid, he just looked down, sadly … [The doctor was] like, that’s my way of making him understand that he needs to lose weight.</td>
</tr>
<tr>
<td>The BMI letter telling them info they knew</td>
<td>I’ve gotten something like this … I was kind of upset ’cause I said, ‘Who are these people?’ I take my kids to the doctor so I already know where they stand.</td>
</tr>
<tr>
<td>The school’s role in BMI screening</td>
<td>This should not be coming from the school system, but I do understand … not everybody constantly goes to their physicians. However, it should be something like, if you don’t see a physician … it really should be coming from a physician and not a nurse from the school.</td>
</tr>
<tr>
<td>A child’s weight based on muscle mass or athleticism</td>
<td>Because a kid with muscle is not obese … I got kids, basketball, football, soccer, and they go to the gym, they lift weights, they run. When they lifting those weights that’s where the muscle comes in – they’ll be thicker, but that’s all muscle right there.</td>
</tr>
<tr>
<td>A child’s weight based on heredity</td>
<td>[My son’s] always going to be bigger than most of the kids so his weight is always going to be more – doesn’t mean he’s any less healthy than any of the children. Some people just don’t thin out like that or some people just stay big or they have bigger bones.</td>
</tr>
<tr>
<td>A child’s weight based on national trends</td>
<td>The doctor should not be critical and they should be understanding because it’s a world problem that we have, it’s not just us here … so I think they should be respectful and mindful of others and not judgmental, and that positive reinforcement, that positive talk, we’re only human.</td>
</tr>
<tr>
<td>A child’s weight based on underlying medical conditions</td>
<td>For my granddaughter, that wasn’t only what we were eating, was the new medication that she was taking increased her appetite and she gained weight, a lot of weight. My son did not eat meat, my son did not drink milk, my son did not eat grease, my son didn’t eat McDonald’s … let’s think about something called thyroids, different metabolism inside the body, which might multiply their growth.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Anger/Upset</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Rationalization</th>
</tr>
</thead>
</table>

| – Continued on next page – |

164
<table>
<thead>
<tr>
<th>Skepticism</th>
<th>Acceptance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BMI as a valid measure of a child’s excess weight</strong></td>
<td><strong>Use of the term chubby if used for young children only</strong></td>
</tr>
<tr>
<td>It seems like you’re profiling him because it seems like, let’s line up five kids, and they’re all the same height, but not all the same weight, not all the same build. It depends – some have taller torso, some have smaller torsos, longer legs – whatever. Where do they come up with this stuff? They’re not doing the water test, they’re not doing the pinching and all that. They’re just doing it by their formula, weight, height, here’s your index, you know?</td>
<td>When [my son] was little my husband would call him chubby wubby, and he does not like that at all anymore. Before it was fine, and now it’s like – no. When they get older something happens. They’re like, don’t call me that.</td>
</tr>
<tr>
<td><strong>Specific weight terms preferable to others (weight, weight problem, unhealthy weight)</strong></td>
<td><strong>Health professionals discussing weight in the context of health</strong></td>
</tr>
<tr>
<td>[Weight is] not bad, I don’t see that as a bad word … We use weight, just check your weight today and how much you weigh. Well, weight problem, I don’t see it as bad as the other words. Weight problem could be just a few pounds or it could be a hundred pounds so I don’t see it as offensive – no. [Unhealthy weight is] not an offensive word. It’s telling you the truth, just straightforward – unhealthy.</td>
<td>I think instead of saying, ‘We’re going to give you a referral to the obesity clinic,’ they should say, ‘We’re going to give you a referral to someone that’s going to help you eat healthier and live a healthier life and show you ways to be more active.’</td>
</tr>
<tr>
<td><strong>Health professionals’ helpful feedback and nutrition advice</strong></td>
<td><strong>The school’s role in BMI screening</strong></td>
</tr>
<tr>
<td>They spoke to my daughter and they said, you know what, when you eat, when you have a piece of chicken, try not to eat another piece. Try to fill up on fruits and vegetables. That’s what I try to get my kids to do, that’s a positive thing. And don’t skip meals, that was one too. I don’t think I ever had any negative, any kind of feedback is good feedback … just telling what kinds of foods to eat, the portion size, how often to eat, what time not to eat at.</td>
<td>It’s actually good that they do it because you get to see – back when you’re younger they never did this so – you just get to see where they compare and where they should be. This is very positive, and I think everybody should get it and get screened … I’m just glad the school noticed and they’re out there to help the kids with their weight.</td>
</tr>
<tr>
<td><strong>Useful information in the BMI letter</strong></td>
<td></td>
</tr>
<tr>
<td>I did get mine in the mail, so I thought it was very helpful … Health-wise a kid can’t even know he has health problems and end up having a heart attack or something just ‘cause he’s overweight.</td>
<td></td>
</tr>
</tbody>
</table>
Table 14. Adults’ Preferred Weight Terms based on the Weight Preferences Questionnaire

<table>
<thead>
<tr>
<th>Study</th>
<th>Study Population</th>
<th>Most Preferred</th>
<th>Least Preferred</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Wadden &amp; Didie, 2003</td>
<td>3 subgroups: • 167 obese women (average age 47.5 yrs, 79% white) • 52 obese men (average age 45.6 yrs, 94% white) • 105 extremely obese women (average age 42.7 yrs, 78% white) Obese participants were in obesity treatment trials; extremely obese, seeking bariatric surgery</td>
<td>Weight* BMI Excess weight Weight problem</td>
<td>Fatness* Excess fat Large size Obesity</td>
</tr>
<tr>
<td>2. Dutton et al., 2010</td>
<td>143 overweight/obese patients seeking weight loss treatment (average age 46.8 yrs, 89.5% female, 64.5% white)</td>
<td>Weight BMI Unhealthy body weight Unhealthy BMI</td>
<td>Fatness Excess fat Large size Obesity</td>
</tr>
<tr>
<td>3. Volger et al., 2011</td>
<td>390 obese patients in a weight loss trial (average age 51.5 yrs, 80% female, 59% white)</td>
<td>Weight* BMI Excess weight Weight problem</td>
<td>Fatness* Excess fat Large size Obesity</td>
</tr>
</tbody>
</table>

*Rating significantly different from all other terms (P<.001). In study 1 for the term fatness, this difference was only significant for the subgroup of 167 obese women.
Figure 1. Distribution of Participants' Literacy Skills Based on Newest Vital Signs

- 17 (59%) Adequate Literacy
- 7 (24%) Possibility of Limited Literacy
- 5 (17%) High Likelihood of Limited Literacy
Let’s Talk About … Words and Weight

Body weight is a personal issue. It can be hard for people to talk about even when they want to be helpful. We want to know how to talk to parents in the most helpful way we can, so we want to hear what you think.

A new Massachusetts law requires school nurses to measure the height and weight of all 1st, 4th, 7th, and 10th grade students. The height and weight information is used to calculate each student's body-mass index (BMI). Schools then send a letter with the BMI results to parents and caregivers.

Researchers from the Baystate Pediatric Weight Management Program and the University of Massachusetts, Amherst Department of Nutrition are conducting a research study to learn what parents think about the BMI letter.

We want to hear from you:
- What are the most helpful ways for doctors, school nurses, and other health professionals talk to you about your child’s weight?
- What are the most helpful ways for doctors and other health professionals talk to you about your weight?
- What words referring to weight are clear and respectful?
- What do you want schools to tell you about your child’s weight?

Who can participate:
- Parents or caregivers of children ages 8-14 in the MIGHTY Program.
- It’s okay if you have not seen the BMI letter yet. Everyone who participates will receive a copy of it.

What you’ll do:
- During one of your twelve MIGHTY exercise sessions, you will take part in a small group discussion instead.
- A researcher from UMass will lead the group in a discussion about your experiences talking to doctors and nurses about weight, your reactions to the BMI letter, and other weight-related issues.

There are no right or wrong answers, we just want to hear what parents like you have to say. Everyone who participates in the study will receive a healthy snack and a $20 gift coupon.

To learn more or sign up:
- Research team members will be at the first MIGHTY class to answer any questions about the study and to get your consent to participate in the study.
- The group discussion will take place during the second class.
APPENDIX B

RECRUITMENT DAY OUTLINE

Introduction

• Introduction of ourselves
• Explain our involvement w/ Baystate/UMass
• Thank them for taking a few minutes to talk with us
• Let them know they may notice me looking at my notes so I don’t forget to tell them anything

About the Study

• Reference the recruitment flyer that they may have seen because it was handed out at some of the MIGHTY program information sessions. [Hold up the flyer to jog their memory.]

• Weight can be a difficult issue to talk about.
• We’re conducting a research study to find out the best ways that doctors, nurses, and other health professionals can discuss children’s weight with parents.

• The state of Massachusetts now requires height and weight measurement for children in 1st, 4th, 7th, and 10th grades. These results are mailed home to parents in a letter.
• You, as parents, are the real experts on this topic! We want to hear your reactions to the BMI letter and we would also like to talk about the words and phrases that are often used to describe weight.

• As part of this project, we’re inviting groups of parents with 8- to 14-year-olds to talk about these questions.
• The discussion group will take an hour and we will provide snacks and a $20 coupon.
• Groups will be held during one of your regularly scheduled exercise sessions. So you would come to the discussion group instead of exercising on one day.

What are your questions?

• OK, so how many of you think you might be interested in participating? Why don’t you come over here with me so that I can tell you everything you need to know.

• For those of you who are interested, we have a couple of things to go over. First, is a consent form. [hand out pens and two copies to each person & clipboards if needed]
Consent Form

- Everyone should have *two copies* of a stapled paper in front of them that says "Research Consent Form." Does anyone need one?
- This form gives you some additional information about the project we are doing. It is fairly detailed, so I'll go over the important points for you now.
- Please stop me at any point if you have questions.

- The first question on the sheet is: *Why are you being asked to take part in this research?*

- We’re asking parents and caregivers of children who are in the MIGHTY program if they would like to take part in a discussion group as part of our project. We want to make sure you know that whether or not you participate is completely up to you. If you do decide to be part of a discussion group, it will help us with our research, but if you decide not to take part, it won’t affect your child’s medical care, your medical care, or your participation in the MIGHTY program in any way.

- This also tells you that the project is being paid through a grant from Baystate and UMass Amherst.

- We’re looking for about 32 parents in total to help us out. Once everyone has signed up, we’ll split you into small groups for the discussion, which is called a “focus group” on this sheet.

- As I said before, the focus group will take about an hour. It will be led by me or another researcher from Baystate or UMass, and we’ll just ask you for your thoughts and opinions. So, there are no right or wrong answers.

- The focus group will be held two weeks from today, when you will be here during the MIGHTY program. If you sign up to participate, the discussion will take the place of your exercise session for that day.

- OK, now I’m on the next page. In bold at the top it just says again that you don’t have to participate in this study if you don’t want to.

- This also says that we are taking a number of steps to keep information from the discussion confidential. We’ll be tape recording the focus groups so that we can remember what everyone had to say. We aren’t going to be talking about anything during the groups that would allow anyone to identify you, and we’ll keep the tapes in a secure, locked area.

- This also explains that there are no costs to you. If you participate, you will help us learn how to communicate with parents better. As a thank you, we will give each person a $20 gift coupon and a snack during the discussion. The gift coupon will probably be to a store like Big Y.
• And then this goes over again the fact that we are going to be careful to keep your identity private, no personal information about you will be reported or published. We are just looking for the thoughts and opinions of the group.

• This also lists the names of a few people you can contact by phone or by email if you have any more questions about this project later on.

• At this point, what questions do you have for me?

• If you’re okay with all of this, I’d like you to fill in the information and sign 2 copies of this form. You can skip the part about the “witness” or “legal representative.” [Go through this part about skipping slowly.] Brenda will also get to sign the forms. One copy is for you and one is for me.

• Brenda will come around and sign and collect one of each of your forms. While she’s doing that, we can move on to our last thing to do.

[Brenda signs & collects Informed Consents, checks for completeness. Lindsay will hand out copy of demographic survey to each person.]

Demographic Survey

• Okay, the last thing we need to do today is this “Demographic Survey.” Does everyone have a copy?

• This has some questions about you that will be helpful for us to know so that any programs we develop from our research can be tailored as much as possible to people like you who will benefit the most from them. When you’re filling this out, please remember that we’re asking for information about YOU, not about your child.

• It asks for your name, but that is only so we can keep track of people who are participating. As we move along with the project and look at the information we’ve collected, we’ll be using “code numbers” to keep track of things, not names. You can see a spot for this code in the grey box.

• Let’s go through each part of this survey now so you can fill it out as we go along. If you have any questions, please stop me so I can answer them.

• OK, in the first line, please fill out your first and last name and today’s date, which is [...]  

• [Go through this part slowly.] You can skip the next two boxes, nutrition educator and group. You can also ignore the next portion that asks
whether you are enrolled in EFNEP. This question was used for the
survey in another group of people.

• In the next section, put your mailing address, including the city, state, and
zip code.

• Below that is a spot for your phone number.

• We need this contact information because I'll be getting in touch with you
briefly the day before the discussion is scheduled. This is just to remind
you of the time and any other last-minute details. This is really important in
case anything changes at the last minute that I need to let you know
about.

• We can either call you or send you a text message. If you would like us to
call you, please write the word “call” next to your phone number. OR, if
you would rather get a text message, please write the word “text” next to
your phone number.

• Next, please write your age, [wait ….] And then circle your gender.

• The next question asks for the highest grade in school you’ve completed.
So if you finished high school or college, you’d put in high school or
college. If you started but didn’t finish, then just put the highest grade you
finished.

• Next, how many children are living in your household? When we say
children we’re asking about anyone who is 19 years old or younger and
lives with you full time.

• Next, we want to know how old the children are who live with you. So for
example, if you said there are three children living with you, you would list
each of their ages separately.

• Next, we would like to know what language you speak most often at
home.

• On the bottom left, please check one of the two terms to describe yourself
that you most identify with: Hispanic/Latino or Non-Hispanic/Latino.
• Finally, on the bottom right, check the category or categories you most
identify with. You can check more than one.

[Brenda and Lindsay collect the surveys and give participants a reminder
sheet at the same time. Check off whether they are getting a phone call or
text message and circle their date/time. Also check to make sure the
surveys are filled out completely.]
Thank You & Next Steps

- Remind them that they will be doing the focus group in place of their exercise session on the day/time circled on the slip handed out.

- Remind them that they will get a text or call beforehand with details.

- Remind them to please be on time so that we can have everyone together to start the focus group. We will be going over important information about how it works and what we'll be covering at the beginning, so it is important for everyone to be there then.

- Thank everyone for their time and for helping us with our project.

[Put consent forms and demographic surveys in separate envelopes and give them to Brenda to go to Baystate.]

[MAKE SURE WE HAVE A LIST OF PARTICIPANTS TO EXPECT FOR EACH FG SESSION.]
APPENDIX C

INFORMED CONSENT FORM

Title of Project: The Massachusetts BMI Letter: How are Parents Responding?
Study Sponsor: Baystate-UMass Collaborative Biomedical Research
Principal Investigators: Sarah Goff, MD and Elena Carbone, DrPH, RD, LDN

WHY ARE YOU BEING ASKED TO TAKE PART IN THIS RESEARCH?
We are talking to you about this research study because you are the parent/caregiver of a child enrolled in
the Moving, Improving and Gaining Health at the YMCA (MIGHTY) program. Whether or not you take part
in this study is up to you. If you choose not to participate in the study it will not affect the quality of medical
care you will receive.

This form gives you important information. Please read it carefully and ask questions before you make a
decision. Please take your time. You should not sign this form until all of your questions are answered.

WHY IS THIS RESEARCH STUDY BEING DONE?
The purpose of this research study is to assess the effectiveness of the Massachusetts BMI screening
report (BMISR) being sent home from schools to parents which reports the children's BMI status. This
study will address four research questions critical to assessing the effectiveness of the BMI letter and
materials: 1) BMISR readability, 2) parents' health literacy level, 3) parents' feelings about language used
for weight-related issues, and 4) parents' responses to BMISR materials.

HOW IS THIS RESEARCH STUDY BEING FUNDED?
This research is being funded through by a Baystate Medical Center and University of Massachusetts
Collaborative Biomedical Research Grant.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?
There will be approximately 32 parents who will be asked to participate in this study. The participants will
be combined into four focus groups of approximately 6-8 parents of children participating in the MIGHTY
program.

HOW LONG WILL YOU BE IN THIS STUDY?
Your participation in this research study is expected to last for one focus group session of 60 minutes
duration.

Consent Version: Final - Date Revised: 10/3/11
PARTICIPATION IN THIS STUDY IS VOLUNTARY

Taking part in this study is voluntary. You can stop taking part in this study at any time. Your decision will not affect your relationship with your doctor or with Baystate Medical Center and will not result in any penalty or loss of benefits to which you are otherwise entitled.

If you do decide to withdraw from the study, the data you contributed will remain in the study. We will not be able to remove the data collected from an individual from the study data because of the anonymous nature of the data collection.

WHAT WILL YOU DO IN THIS STUDY?
If you are found eligible to participate in this study you will participate in 2 parts of this study. You will be asked to 1) complete a brief assessment of your literacy level, the Newest Vital Sign and 2) participate in a focus group to discuss the weight-related language and the Massachusetts BMI letter sent home by public schools. The focus group is a discussion session with other parents in your MIGHTY group that is led by a research team member. It will last for 60 minutes and will be audio-taped with permission of participants. We will ask you to fill out a short form about yourself but no personal identifying information will be contained in this form asked and no information that could result in you being identified will be asked in the discussion. Any portions of audio tapes with personal information that come out in the course of discussion will be deleted.

WHAT RISKS OR PROBLEMS COULD YOU HAVE BY BEING IN THIS STUDY?
Potential risk to you is the possibility of slight embarrassment in discussing weight-related issues. There is also a small risk of loss of confidentiality, which we are taking numerous measures to prevent including deletion of personal information of tapes and use of a careful data storage plan.

WILL YOU BENEFIT FROM BEING IN THIS STUDY?
You may or may not benefit from being in this study. What we learn from this research study may help other people understand how parents prefer issues regarding weight be discussed and to improve the BMI letter in the future.

WILL THERE BE ANY COSTS TO YOU?
There are no costs to you to participate in this research study.

WILL YOU RECEIVE ANY COMPENSATION?
To thank you for your time in participating in this study you will receive a $20.00 gift coupon and a healthy snack during the focus group meeting.

HOW WILL YOUR PRIVACY BE PROTECTED?
We will protect your privacy as a participant in this research study and the confidentiality of your research information. Research information that is sent outside of Baystate Medical Center (for example, to UMASS for transcription) will not have your name on it and will be sent in an encrypted email.

If we publish information from this research study or use it for teaching, your name will not be used.

We are asking for your permission to make audiotapes of the focus group sessions.
WHO DO YOU CONTACT IF YOU HAVE STUDY QUESTIONS OR CONCERNS?

If you have any questions about this study, please contact: Sarah Goff, MD at 794-0816 or Elena Carbone, DrPH at 413-545-1071. If you experience a complication or injury that you believe may be related to this study, please contact: Dr. Goff at 794-0816 or Dr. Carbone at 413-545-1071. After hours, please call 794-0816 and ask the resident on call to contact Dr. Goff.

If you would like to discuss your rights as a research participant, or wish to speak with someone not directly involved in the study, please contact the Baystate Medical Center Institutional Review Board at (413) 794-4356 and/or the University of Massachusetts Amherst Human Research Protection Office (HRPO) at (413) 545-3428 or humansubjects@ora.umass.edu.
STATEMENT OF VOLUNTARY CONSENT

I have read this form or have had it read to me. I have been told what to expect if I take part in this study, including possible risks and possible benefits. I have had a chance to ask questions and have had them answered to my satisfaction. I have been told that the people listed in this form will answer any questions that I have in the future. I also understand that one of the principal investigators is employed at Baystate Medical Center and one is employed at UMass, which are the funding agencies for this study. By signing below, I am volunteering to be in this research study.

Participant’s Name (Print):  
Signature:  
Date:  

Legal Representative’s Name (Print):  
Relationship to Participant (ex. Parent, Spouse, Legal Guardian) (Print):  
Signature:  
Date:  

Witness’s Name (Print):  
Signature:  
Date:  
Witness to:  

You will receive a copy of this form after it has been signed and dated.

STUDY REPRESENTATIVE STATEMENT

I have explained the purpose of the research, the study procedures, the possible risks and discomforts, the possible benefits, and have answered all questions to the best of my ability.

Study Representative’s Name (Print):  
Signature:  
Date:  
Time Consent Obtained:  

Consent Version: Final - Date Revised: 10/3/11  
Page 4 of 4
APPENDIX D

DEMOGRAPHIC SURVEY

Note: Participants were instructed to indicate whether they preferred a call or text message, not an email.
Focus Group Reminder

Your focus group will meet on: (Circle option below)

 Tuesday, October 25th at 3:00 pm

 Tuesday, October 25th at 4:00 pm

 Wednesday, October 26th at 3:30 pm

 Thursday, October 27th at _______ pm

You will also receive a _____ phone call or _____ text message from us to remind you the day before your group.

 Thank you!
APPENDIX F

PHONE CALL SCRIPT

Hello, may I please speak to [first and last name] __________?

Hi, [use Mr/Mrs here]______, my name is Lindsay I'm a graduate student at UMass. I'm calling about the focus group discussion you signed up to participate in during tomorrow's MIGHTY class.

I just wanted to remind you that it begins at 3pm/4pm/3:30pm and will last an hour. It will take the place of your regularly scheduled exercise time tomorrow.

When you arrive at 3pm/4pm/3:30pm, Hilary or Kara will be in the lobby to show you where the discussion group will be.

It's really important to arrive on time because the discussion will take the entire hour.

Do you have any questions?

Thank you so much for agreeing to participate. I'm really looking forward to our discussion. I'll see you tomorrow at the YMCA at 3pm/4pm/3:30pm.
APPENDIX G

TEXT MESSAGE SCRIPT

This is a reminder about the focus group discussion you signed up for during MIGHTY class tomorrow at [3pm/4pm/3:30pm]. Please ask Kara or Hilary to direct you to us. Thanks!

Note: This message is less than 160 characters, the length of one text message if you don't have a phone such as the iPhone that shows an unlimited amount of characters together.
APPENDIX H

NEWEST VITAL SIGN

Implementation Guide for the Newest Vital Sign

Health literacy — the ability to read, understand and act upon health information — is now known to be vital to good patient care and positive health outcomes. According to the Institute of Medicine’s groundbreaking report on health literacy, nearly half of all American adults — 90 million people — have difficulty understanding and using health information. When patients lack the ability to understand and act upon medical information, it can put their health at risk.

The Newest Vital Sign is a new tool designed to quickly and simply assess a patient's health literacy skills. It can be administered in only 3 minutes and is available in English and Spanish. The patient is given a specially designed ice cream nutrition label to review and is asked a series of questions about it. Based on the number of correct answers, health care providers can assess the patient’s health literacy level and adjust the way they communicate to ensure patient understanding.

There are many ways to integrate the Newest Vital Sign (NVS) into a private practice or clinic setting to improve communication with patients. Improved communication can help increase your patients’ ability to understand and act upon the information you provide; ultimately improving patient satisfaction and health outcomes.

How To Use the Newest Vital Sign

1. Who and when to administer the Newest Vital Sign.
   - A nurse (or other trained clinic staff) is the preferred administrator of the Newest Vital Sign.
   - Administer at the same time that other vital signs are being taken.

2. Ask the patient to participate.
   A useful way to ask the patient is an explanation similar to this:
   “We are asking our patients to help us learn how well patients can understand the medical information that doctors give them. Would you be willing to help us by looking at some health information and then answering a few questions about that information? Your answers will help our doctors learn how to provide medical information in ways that patients will understand. It will only take about 3 minutes.”

3. Hand the nutrition label to the patient.
   The patient can and should retain the nutrition label throughout administration of the Newest Vital Sign. The patient can refer to the label as often as desired.

More...
4. Start Asking the 6 questions, one by one, giving the patient as much time as needed to refer to the nutrition label to answer the questions.
   - There is no maximum time allowed to answer the questions. The average time needed to complete all 6 questions is about 3 minutes. However, if a patient is still struggling with the first or second question after 2 or 3 minutes, the likelihood is that the patient has limited literacy and you can stop the assessment.
   - Ask the questions in sequence. Continue even if the patient gets the first few questions wrong. However, if question 5 is answered incorrectly, do not ask question 6.
   - You can stop asking questions if a patient gets the first four correct. With four correct responses, the patient almost certainly has adequate literacy.
   - Do not prompt patients who are unable to answer a question. Prompting may jeopardize the accuracy of the test. Just say, “Well, then let’s go on to the next question.”
   - Do not show the score sheet to patients. If they ask to see it, tell them that “I can’t show it to you because it contains the answers, and showing you the answers spoils the whole point of asking you the questions.”
   - Do not tell patients if they have answered correctly or incorrectly. If patients ask, say something like: “I can’t show you the answers till you are finished, but for now you are doing fine. Now let’s go on to the next question.”

5. Score by giving 1 point for each correct answer (maximum 6 points).
   - Score of 0-1 suggests high likelihood (50% or more) of limited literacy.
   - Score of 2-3 indicates the possibility of limited literacy.
   - Score of 4-6 almost always indicates adequate literacy.

Record the NVS score in the patient’s medical record, preferably near other vital sign measures.

Best Practices for Implementation: Summary

- A nurse (or other trained clinic staff) is the preferred administrator of the Newest Vital Sign.
- Administer the NVS at the same time that the patient’s other vital signs are being taken.
- Record the NVS score in the patient’s chart, preferably near other vital sign measures.
- Tailor communication to ensure patient understanding.
**Nutrition Facts**

<table>
<thead>
<tr>
<th>Serving Size</th>
<th>½ cup</th>
</tr>
</thead>
<tbody>
<tr>
<td>Servings per container</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Amount per serving</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Calories</td>
<td>250</td>
<td></td>
</tr>
<tr>
<td>Fat Cal</td>
<td>120</td>
<td></td>
</tr>
<tr>
<td>%DV</td>
<td>20%</td>
<td></td>
</tr>
</tbody>
</table>

| Total Fat | 13g | 20% |
| Sat Fat   | 9g  | 40% |
| Cholesterol | 28mg | 12% |
| Sodium    | 55mg | 2%  |
| Total Carbohydrate | 30g | 12% |
| Dietary Fiber | 2g  |     |
| Sugars     | 23g  |     |
| Protein    | 4g   | 8%  |

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

**Ingredients:** Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.
# Score Sheet for the Newest Vital Sign

**Questions and Answers**

**READ TO SUBJECT:**
This information is on the back of a container of a point of ice cream.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>ANSWER CORRECT?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>1. If you eat the entire container, how many calories will you eat? &lt;br&gt;<strong>Answer:</strong> 1,000 is the only correct answer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have? &lt;br&gt;<strong>Answer:</strong> Any of the following is correct: 1 cup (or any amount up to 1 cup), half the container. Note: If patient answers “two servings,” ask “How much ice cream would that be if you were to measure it into a bowl?”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day? &lt;br&gt;<strong>Answer:</strong> 33 is the only correct answer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. If you usually eat 2,500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving? &lt;br&gt;<strong>Answer:</strong> 10% is the only correct answer</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Is it safe for you to eat this ice cream? &lt;br&gt;<strong>Answer:</strong> No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. [Ask only if the patient responds “no” to question 5]: Why not? &lt;br&gt;<strong>Answer:</strong> Because it has peanut oil.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

REVISED NEWEST VITAL SIGN

Newest Vital Sign Script

What I’d like to do now is a short activity looking at the nutrition label that’s on food packages.

The reason we’re doing this is to find out how easy or hard it is to understand the information on the label.

You should have a copy of a nutrition label activity sheet [hold this up] in front of you. Go ahead and put your name on the top of the activity sheet.

[Wait and check that everyone has written their name.]

You’ll be using the activity sheet to write in your answers to each of my questions. Please don’t say your answers out loud because I want to know what each of you are thinking. There are only 6 questions, so do the best you can. It’s okay if you don’t know the answer to a question. If that happens, you can just leave it blank and we’ll go on to another question.

What are your questions?

OK, please take a look at the nutrition label. You’ll be using this to answer the questions I’ll be asking. As it turns out, this information is on the back of a container of a pint of ice cream.

Please write ONLY your ANSWERS to the questions on this piece of paper. You can write them on the numbered lines below the food label.

Question #1 is: If you eat the entire container, how many calories will you eat?

Let me repeat that.

Now, for question number 2. If you are allowed to eat 60 grams of carbohydrate as a snack, how much ice cream could you have?

[Repeat once.]

OK, Question #3 is a longer one, but I’ll repeat it! Your doctor advises you to reduce the amount of saturated fat in your diet. [pause] You usually have 42 g of saturated fat each day, which includes one serving of ice cream.
If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?

We’re half way through!

Now for question number four. If you usually eat 2500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving of ice cream?

For question number five, I’d like you to pretend that you are allergic to the following substances: Penicillin, peanuts, latex gloves, and bee stings. Is it safe for you to eat this ice cream? Please answer yes or no.

When I have used this activity with other groups before, some people say yes for the previous question and others say no. For the final question, question #6, I only need you to listen if you wrote “no” for question #5. If you wrote “yes,” you can leave number six blank.

Final question: Why isn’t it safe for you to eat the ice cream?

OK, that’s it for the nutrition label. Thanks very much for helping me with this.
Newest Vital Sign Participant Answer Sheet

Your name: ___________________________________________

Nutrition Facts

<table>
<thead>
<tr>
<th>Serving Size</th>
<th>½ cup</th>
</tr>
</thead>
<tbody>
<tr>
<td>Servings per container</td>
<td>4</td>
</tr>
<tr>
<td>Amount per serving</td>
<td></td>
</tr>
<tr>
<td>Calories</td>
<td>250</td>
</tr>
<tr>
<td>Fat Cal</td>
<td>120</td>
</tr>
<tr>
<td>%DV</td>
<td></td>
</tr>
<tr>
<td>Total Fat</td>
<td>13g</td>
</tr>
<tr>
<td>Sat Fat</td>
<td>9g</td>
</tr>
<tr>
<td>Cholesterol</td>
<td>28mg</td>
</tr>
<tr>
<td>Sodium</td>
<td>55mg</td>
</tr>
<tr>
<td>Total Carbohydrate</td>
<td>30g</td>
</tr>
<tr>
<td>Dietary Fiber</td>
<td>2g</td>
</tr>
<tr>
<td>Sugars</td>
<td>23g</td>
</tr>
<tr>
<td>Protein</td>
<td>4g</td>
</tr>
</tbody>
</table>

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


Question #1: _________________

Question #2: _________________

Question #3: _________________

Question #4: _________________

Question #5: _________________

Question #6: _________________

Thank you!
Dear Parent or Guardian:

Your child, _______________________________________, was weighed and measured as part of the Body Mass Index (BMI) Screening Program. BMI is a way we can check to see if your child has a healthy weight. The results of the screening compare your child’s height and weight to other children of the same age and sex. The results are given as a “percentile.” Your child’s BMI is only being shared with you. No one else will see these results.

Your child’s results were:
Height: _____ ft. _____ in.          Weight: ________ lbs.  BMI Percentile: ________

- Underweight – less than the 5th percentile
- Healthy weight – 5th percentile to less than the 85th percentile
- Overweight – 85th percentile to less than the 95th percentile
- Obese – 95th percentile or greater

If your child’s BMI is below the 5th percentile, he or she may be underweight. If your child’s BMI is above the 85th percentile, he or she may be overweight or obese. If your child is not in the healthy weight range, you should talk with your child’s doctor or nurse. He or she can give you ideas about how to help your child get to a healthy weight.

Your child’s weight category is:
Underweight_______
Normal weight_______
Overweight_______
Obese_______

You may have talked about your child’s weight with your doctor or nurse before, but you can use these screening results to talk with them again. If your child does not have a regular doctor or does not have health insurance, please contact me.

BMI may not tell the whole story about your child’s weight. Other things can affect your child’s BMI. For example, BMI cannot tell the difference between muscle and fat. An athletic child with a lot of muscle may have a high BMI but not be overweight.

I am including information with this letter to help you learn more about what you can do to make sure your child is healthy. You can also learn more at the Department of Public Health’s website www.Mass.Gov/MassInMotion. If you have any questions, please call me at ________________.

Sincerely,
Help your kids eat healthy at home.

When you go food shopping, read the label. Choose healthy foods.

- Choose 100% whole grain breads. The first ingredient on the label should start with "whole," like "whole wheat flour."
- Choose cereals that are low in sugar and made from whole grains. Read the label and look for rolled oats, whole wheat, brown rice, rye, barley, triticale or buckwheat. A cereal could be made from one or all of these grains. Oatmeal is a good choice.
- Choose chicken and fish instead of beef.

For healthy snacking, keep these foods in the refrigerator:

- A bowl of fruit. Try slices of apple, fresh berries, orange slices, or cut up pineapple or mango. Keep the bowl covered with plastic wrap to keep the fruit fresh.
- A bowl of fresh vegetables. Try cucumber sticks, carrots sticks, celery sticks, broccoli, slices of red pepper and green pepper, or slices of zucchini.
- Slices or chunks of low fat cheese.
- Non-fat or low fat yogurt for kids over 2 years old. It's good alone or used as a dip for fruits and vegetables. Children under 2 can have yogurt made from whole milk.
- Non-fat or low fat milk for kids over 2 years old. It's healthier than juice. Children under 2 should drink whole milk.

Do these simple things to make each meal healthier:

- Add 1 to 2 slices of low fat cheese to a sandwich.
- Serve milk or soy milk with meals.
- Make meals that have more vegetables and beans and less meat.
- Broil, bake, grill or steam your food.

Other easy tips for healthy eating:

- Give kids water to drink during snack time and when they're thirsty. Serve milk with meals.
- Serve a healthy breakfast, such as whole grain cereal or toast, along with fruit and milk.
- Turn off the TV during meals and enjoy your meals together.
- Remember that kids will do what you do. If you make healthy choices, they will too!
- Go to www.mass.gov/MassInMotion to find more tips on healthy eating.
Give your kids the right amount of food.

How much a child should eat depends on their age. This chart shows how much children should eat each day based on how old they are:

<table>
<thead>
<tr>
<th>Food</th>
<th>2-5 years old</th>
<th>6-10 years old</th>
<th>11 to 13 years old</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fruits</td>
<td>1 to 1½ cups</td>
<td>1 to 1½ cups</td>
<td>1½ to 2 cups</td>
</tr>
<tr>
<td>Vegetables</td>
<td>1 to 1½ cups</td>
<td>1½ to 2 cups</td>
<td>2 to 2½ cups</td>
</tr>
<tr>
<td>Grains</td>
<td>3 to 5 ounces</td>
<td>5 to 6 ounces</td>
<td>6 to 7 ounces</td>
</tr>
<tr>
<td>Dairy: low or non-fat</td>
<td>2 cups</td>
<td>2 to 3 cups</td>
<td>3 cups</td>
</tr>
<tr>
<td>Lean meats, fish, chicken,</td>
<td>2 to 4 ounces</td>
<td>4 to 5 ounces</td>
<td>5 to 6 ounces</td>
</tr>
<tr>
<td>beans, legumes or eggs</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How much is a cup of fruits or vegetables?

- A cup is about the size of a baseball. Many oranges, apples and peaches are this size.
- For vegetables, it’s good to remember that two cups of raw vegetables will cook down to about a cup.

How much is a cup of dairy?

One cup of dairy equals:

- 1 cup of low fat or non-fat milk or yogurt – the size of a baseball
- 1 ½ ounces of cheese – 4 dice-sized pieces

What foods have an ounce of grain?

- 1 slice of whole grain bread
- ½ cup whole grain or enriched pasta or rice (You can tell it’s enriched because it will say "enriched" on the front of the box or bag.)
- 1 cup of whole grain cold cereal or ½ cup enriched cooked cereal

How much is an ounce of meat and other protein?

- 3 ounces of meat or fish is as big as a deck of playing cards.
- Instead of meat, you can also feed your child:
  - 1 egg
  - 1-2 tablespoons peanut butter
  - ¼ cup cooked lentils or beans, navy beans or kidney beans

Provided by the Nutrition and Physical Activity Unit, Massachusetts Department of Public Health | 2009
APPENDIX L

PHYSICAL ACTIVITY SHEETS MAILED WITH THE BMI LETTER

Your child needs to be active every day.

Getting at least 1 hour of activity every day will help your child grow up healthy. An active child:
» Sleeps better at night
» Has a healthy weight
» Grows strong bones and muscles
» Feels better about themselves
» Gets along better with other kids
» Has more confidence when playing games and sports
» Does better at solving problems and thinking about things
» Does better in school

You can make active time more fun for your preschooler.
Your preschool child will be active most of the day without needing help from you. You can make it more fun by planning an hour of fun activities every day. Here are some ideas:
» Limit TV to 30 minutes each day or turn it off.
» Play games like Simon Says, Chase, Tag, Hopscotch, Red Light – Green Light.
» Show your child how to ride a tricycle – don’t forget the helmet!
» Put on some of your favorite music and dance around together.
» Take your child to the local park and let them use their imagination as they explore and run around.
» Join tumbling or dance classes offered by the Y or recreation department in your town.
» Team up with other parents who have preschoolers and arrange for play dates.
» Walk the family dog together.
» Take your child outside and give them room to run and holler.

Keep your preschooler safe.
Preschoolers are very active and every day is an adventure. They need to be watched every moment because they haven’t learned how to be safe. Make sure your child wears a helmet when riding a tricycle and do safety checks on the play equipment.

Provided by the Nutrition and Physical Activity Unit, Massachusetts Department of Public Health | 2009
Make active time even more fun for your child.

» Show your child it’s good to be active by being active yourself. Children want to do what you do.
» Find out what activities your child likes or would like to try and then help them do it.
» Have your child show you the activities they do in school. Do them together as a family.
» Do activities as a family. Go for walks, hike, ride bikes, rollerblade or roller-skate, play tag or play sports like basketball and volleyball.
» Turn off the TV or allow only one hour of TV time each day.
» Limit the amount of time your child spends e-mailing friends or playing games on the computer.
» If it’s safe, let your child walk or bike to school.
» Get children to help with housework, walking the dog, washing the car, gardening or mowing the lawn.
» Go to the family swim at the YMCA, health club or community pool.
» Encourage your child to play sports and games with friends, like tag or dodgeball.

Make sure your child uses safety gear.

» When biking, a child should always wear a helmet.
» For some activities, like rollerblading or skateboarding, a child should wear elbow and knee pads.

All children, regardless of ability, should enjoy the benefits of being active.

» If your child has a disability, there are still plenty of ways for them to be active. Check with your doctor or nurse for advice.

Here’s where you can go for more ideas for fun activities, including adapted physical activity opportunities for kids with disabilities:

» Check your local library, YMCA or local recreation department in your town.
» Call your local school district and talk to your school’s adapted physical education teachers.
» Check the National Center for Physical Activity and Disability’s Program Directory at www.ncpad.org for more adapted physical activity resources in your area.
» Go to www.mass.gov/MassInMotion to find other ideas in your town.
APPENDIX M

FAQS ABOUT BMI MAILED WITH THE BMI LETTER

Frequently Asked Questions About Body Mass Index (BMI) Screening

- **What is BMI?**
  BMI stands for Body Mass Index. It is a way of checking to see if your child has a healthy weight. The results of the screening compare your child’s height and weight to other children of the same age and sex. The results are given as a “percentile.” The percentile shows how a child’s BMI compares to others of the same age and sex. In general, the higher the BMI, the more fat there is in the body.

  Below are examples of percentiles for BMI.

  ![Percentile Chart]

  - Underweight – less than the 5th percentile
  - Healthy weight – 5th percentile to less than the 85th percentile
  - Overweight – 85th percentile to less than the 95th percentile
  - Obese – 95th percentile or greater

- **Why are schools doing BMI screening?**
  The Massachusetts Department of Public Health (DPH) wants to help all people in Massachusetts be healthy and part of that is maintaining a healthy weight. People who are overweight or obese can have serious health problems. There can also be serious problems for people who are underweight. Parents who have information about their children’s BMI and ideas about how to help their children with healthy living can make sure their kids are at a healthy weight. Community leaders who have information about how many children in their community are in each weight range can work with parents, school officials, after school programs and many others, to come up with ideas to help even more children get into a healthier weight range.

  Public schools have been measuring the height and weight of students for many years as part of yearly growth screening. Recently, the Department of Public Health (DPH) passed a law that requires schools to use this information to calculate BMI for students in grades 1, 4, 7, and 10. It also requires schools to share the BMI results with the child’s parents or guardians in a way that keeps the results private.

- **Why doesn’t the law require screenings every year?**
  Grades 1, 4, 7 and 10 were chosen because of the growth that happens in those age groups. Schools can do BMI screenings in more grades if they would like. The law only says that BMI screening must happen in at least those four grades.

Frequently Asked Questions: BMI Screening - Page 1 of 3
• **Why is BMI screening important to public health officials?**
  For each school, BMI results from individual children will be combined into a summary of how many children are in each BMI category. Each school’s summary will be sent to DPH -- *they will not have any results for an individual child*. No one but a child’s parents or guardians will know his or her results. The summary results will help DPH follow how children’s BMIs in specific communities and throughout the state are changing over time. It is important for DPH to have accurate community-level information about this to plan its public health and prevention programs.

• **Why is BMI screening important to children and families?**
  BMI is way to detect possible weight problems for children. A BMI below 5th percentile may mean that a child is not growing well or that he or she may be at risk for an eating disorder. Children with a BMI above 85th percentile are overweight. Those above 95th percentile are obese. Overweight or obese kids are more likely to be overweight adults. This puts them at risk for a number of health problems like diabetes, high blood pressure, heart disease and stroke.

• **How will the school protect my child’s results so they are not teased or embarrassed by other students?**
  Schools have been measuring heights and weights for many years and are very good at keeping the results private. Results will be mailed to parents or guardians or discussed at an in-person meeting. The new law requires schools to make sure the results are not shared with anyone else.

• **Should I talk to my doctor or nurse about the results?**
  It is always good to talk with your child’s doctor or nurse about information like this. Your doctor may have talked with you about your child’s weight before, but you can use these screening results to talk with them again. If your child’s BMI concerns or surprises you, you should talk with your child’s doctor or nurse before your next well child visit, which may not be for awhile.

• **Is it possible that a child with a high BMI isn’t overweight?**
  Many things can affect BMI, like family history and amount of muscle. BMI cannot tell a difference between muscle and fat, so if a child is very athletic and has a lot of muscle, his or her BMI can be high, even though he or she is not overweight. Your child’s doctor or nurse can help you understand what your child’s BMI screening results mean for him or her.

• **What can I do to help my child be healthier?**
  You can talk with your child’s doctor about his or her BMI. You can also help your child eat 3 balanced meals a day. These meals should include fruits and vegetables, whole grains, lean meats and fish, and low-fat or non-fat milk. You should limit foods high in sugar and fat. For example, avoid soda and other foods that have lots of calories but no nutritional value.
In addition, you should encourage your children to be active for at least an hour each day and limit how much time they spend watching TV or playing on the computer. You can support your school’s efforts to increase physical activity during the school day and provide healthy food options. You can also work with other community leaders and local organizations to make sure healthy food and safe, affordable places to be physically active are available in your neighborhood.

- **How should I talk with my child about his or her results?**
  You can start by saying that the BMI screening gives you and your child information about how he or she is growing. Rather than talking about BMI, you can talk about ways to stay healthy and active.

  If you and your child have talked about these topics before, either at home or in the doctor’s office, you can remind your child how this fits in with what you have already discussed. You can also ask your child if he or she has any questions about the program. Encouraging your child to share feelings about his or her growing and changing body will let him or her know it is okay to talk about these things with you.

- **What other information is available to help me?**
  Talk to your child’s doctor or school nurse, and visit the Mass In Motion website (www.mass.gov/MassInMotion) for more ideas on how to eat better and move more.
### APPENDIX N

**SAM+CAM INSTRUMENT**

<table>
<thead>
<tr>
<th>SAM + CAM Sheet</th>
<th>Reviewers: ☐ ☐ ☐</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title:</td>
<td>Category:</td>
</tr>
<tr>
<td>Text Purpose/Type:</td>
<td>(information, instruction, argumentation, documentation, narration)</td>
</tr>
</tbody>
</table>

#### Evaluation Criteria

<table>
<thead>
<tr>
<th>Category</th>
<th>Score</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Content</strong></td>
<td>(1) Content</td>
<td></td>
</tr>
<tr>
<td>Superior: Purpose of material explicitly stated at the start (title, introduction) or in first 2/3 of the material. <em>(Ex. of explicit statement: The purpose of this booklet is to..., which will make you more comfortable...)</em></td>
<td>Variable 1: Purpose</td>
<td>• Helps reader to easily understand the intended purpose of the material. If they don’t “get” this, they may miss the main point(s). <em>(Read through material 1” to determine if purpose/title relates to what’s covered.)</em></td>
</tr>
<tr>
<td>Adequate: Purpose not explicit, but implied, and toward the beginning of the material. Multiple purposes may be stated.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not suitable: No purpose clearly stated, either explicitly or implicitly.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Superior: A summary (¶, box or clear section of material) clearly reviews or retells the key messages/points in words, examples and/or visuals. <em>(Note: In longer material (chapter) several reviews or summaries included)</em></td>
<td>Variable 2: Summary/Review</td>
<td></td>
</tr>
<tr>
<td>Adequate: Summary is present with some key ideas reviewed clearly. Longer text may only provide one review section.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not suitable: No summary or review of key points is included.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Superior: Desired reader actions/behavior(s) clearly described. Emphasis on what reader must know and do. Throughout text 2 to 3 of the following factors found:</td>
<td>Variable 3: Desired Reader Behavior</td>
<td></td>
</tr>
<tr>
<td>☐ Clearly explains how to/gives examples of how to convey info/ask questions of doctor, use condom, talk with partner, prepare for Pap test.</td>
<td>• Look for especially in prevention materials.</td>
<td></td>
</tr>
<tr>
<td>☐ Includes expected benefits from doing act</td>
<td>• If not applicable in newspaper article or other text, put NA.</td>
<td></td>
</tr>
<tr>
<td>☐ Addresses potential barriers/costs to be overcome</td>
<td>• May be in form of an advertisement; i.e., “Free pap tests available, go to Free Clinic at 1st and Broadway on Tuesday between 1-3pm.”</td>
<td></td>
</tr>
<tr>
<td>Not suitable: Little to no text coverage of acts/behavior(s); focus of material mainly on explaining disease.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2 points = for superior rating  
1 point = for adequate rating  
0 points = for not suitable rating  
NA = factor does not apply

*Note: for health system materials (like consent forms), use shaded boxes only.*
<table>
<thead>
<tr>
<th>Evaluation Criteria</th>
<th>Category</th>
<th>Score</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Literacy Demand</td>
<td>(2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Superior: Writing addresses the reader/patient perspective—what &amp; how they want to know.</td>
<td>Literacy Demand</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Throughout text 3 to 4 are present most of the time:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Sentences are written in active, direct style</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Sentences written in personal, conversational style.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Concrete, common words &amp; concepts used as much as possible, rather than abstract or colloquial words/style.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Most sentences are simple with no embedded information (long, multiple phrases in sentence).</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adequate: At least 2 of the above factors present.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not suitable: None of the above present, i.e. use of medical format to present information, as from doctor’s point of view. Mainly passive, indirect and neutral style; complicated sentence structure. Content generally abstract.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Superior: Includes the following 2 factors:</td>
<td>Vocabulary Helpers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Common, explicit words that are clear and specific in meaning used most of the time (ex: doctor versus physician, exam versus examination, screening test vs. cancer test or Pap test for cancer)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Examples given to explain or clarify difficult words, concepts or category words if they occur most of the time (ex of concepts: range of abnormal Pap results, high risk versus low risk HPV types).</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adequate: 1 of the above factors exists.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not suitable: None (0) of the superior factors exists; jargon (medical terms) used extensively.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Use “N” to indicate if box/factor is irrelevant.

Potential categorical words that often need explanation: screenings, cell, activities, signs and symptoms, health risk behaviors. Clearer: Say risk reducing behaviors like: not smoking, getting a Pap test once a year, etc.
<table>
<thead>
<tr>
<th>Evaluation Criteria</th>
<th>Factor to be Rated</th>
<th>Score</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Numeracy</td>
<td>(3) Numeracy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Superior: 3 of 4 of the following factors present:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Numbers, if used, are present in form other than in use of fractions, percents (except 100%) and/or probabilities,</td>
<td>Variable 10: Numeric Presentation</td>
<td></td>
<td>Does not include such things as telephone #s, addresses, or years.</td>
</tr>
<tr>
<td>Very limited use of percents, other than 100% (or 50%—though “half” better)</td>
<td></td>
<td></td>
<td>If no #s used or present score as NA</td>
</tr>
<tr>
<td>Amounts/costs/rates have helpers like “same as,” less/ more/ than,” or “greater than” to help readers determine meaning of numbers.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequencies (3 out of 10,000) used rather than probabilities (.0003).</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adequate: 2 of 1 factors present in most of the text/material.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not suitable: Fractions, percents or probabilities used often. Amounts/costs not have helpers to determine if amount is more or less.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Evaluation Criteria</th>
<th>Factor to be Rated</th>
<th>Score</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Numeracy</td>
<td>(3) Numeracy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Superior: 2 to 3 factors occur most of the time:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More explanatory/illustrative expressions used instead of value judgment words (ex: “runny nose, not excess mucus,” get Pap test every year, not get Pap test regularly.)</td>
<td>Variable 7: Confusion Reducers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metaphors, similes, analogies, if/when used, help explain or clarify a point or concept (rather than confusing it)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nouns or noun phrases generally replace ambiguous pronouns, unless it’s absolutely clear what the pronoun refers to (ex: put gold on the balance; how much does it weigh?)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adequate: One (1) of the above factors found. Not suitable: None of the superior factors exist.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Superior: Most of the time, both are present:</td>
<td>Variable 8: Context</td>
<td></td>
<td>Ex. Material: Recommend Pap tests without giving any background/image of female anatomy (cervix), why done, etc.</td>
</tr>
<tr>
<td>Material provides background before presenting new information, sentences give more familiar concepts/context before introducing new information (see exs).</td>
<td></td>
<td></td>
<td>Ex. Sentence: To find out what’s wrong with you, the doctor will take a sample of your blood for lab tests. (or) During your colposcopy, tell your doctor if you feel pain or faint.</td>
</tr>
<tr>
<td>Adequate: Addresses 1 of the above factors at least half of the time.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not suitable: Little to no background, or familiar concepts NOT provided before new information.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Superior: 2 to 3 factors found:</td>
<td>Variable 9: Scope &amp; Length</td>
<td></td>
<td>Length in pages: ____</td>
</tr>
<tr>
<td>If there’s a clear, stated purpose [see Var. 1], scope/content limited to essential information directly related to that purpose,</td>
<td></td>
<td>Length in columns/pages (newspaper):____</td>
<td></td>
</tr>
<tr>
<td>Content presented as concisely as possible (less detailed; not too broad in nature),</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In lengthier text, content broken down into or chunked into several concise topics.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adequate: 1 of the above factors found.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not suitable: None of the superior factors found, i.e. scope/content far out of proportion to purpose. Hard to identify key points; material too lengthy and/or detailed.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

©University of New Mexico Health Evaluation & Research Office (505) 272-1601
Revised August 14, 2006

3
<table>
<thead>
<tr>
<th>Evaluation Criteria</th>
<th>Factor to be Rated</th>
<th>Score</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Graphic Material</strong></td>
<td>4 Graphics*</td>
<td></td>
<td>*Graphics are “documents” like tables, charts, graphs, lists. Illustrations/anatomical drawings are considered graphics, but are not documents.</td>
</tr>
</tbody>
</table>

**Superior:** 4 to 6 of the following factors found:
- Throughout text: use of charts, graphs, tables is limited,
  When used,
- Documents are simple and easy to understand (most often shown in simple line graphs, bar charts, histograms and dot charts),
- Documents have explanatory captions
- Documents have examples or “how to” directions to aid understanding
- Documents have low data-ink ratio (ink used to display features other than the data),
- Documents (tables, charts) presented in simple- or combined-list formats.

**Adequate:** 2 to 3 superior factors found in documents (tables/charts).

**Not suitable:** 1 or no superior factors found in documents (tables/charts) OR too many complex graphics exist without adequate explanation.

---

**Variable 11: Calculation**

Example of explicit calculation: Determine your level/percent of risk; given your risk factors, figure out which percent risk category you fit into; you must pay 20% of the charges. If no numbers, mark as NA.

---

**Variable 12: Document Clarity**

(If no graphics/tables/charts, mark as NA) * Note to reviewers: Material with a document (chart, table) must be assessed with PMOSE/IKIRSCH.

---

**Variable 13: Illustrations**

(If no illustrations, mark as NA. If, however, text is lengthy and there are no visual aids, mark as not suitable.)

Do not count logos as visuals, unless relevant to text/meaning.

If image on the front cover, should relate to the title.

---

© University of New Mexico Health Evaluation & Research Office (505) 272-1601
Revised August 14, 2006
### Evaluation Criteria

<table>
<thead>
<tr>
<th>Factor to be Rated</th>
<th>Score</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Layout and Typography</strong></td>
<td>(5) Layout/Typography</td>
<td></td>
</tr>
</tbody>
</table>

**Superior:** Throughout entire text or material 5 or more of the following are present:
- Layout & sequence of info organized logically and consistent throughout material.
- Visual cuing devices (bold, boxes, arrows) direct attention to specific points/key content.
- Adequate white space; no dense text/clutter.
- Use of color supports message (not distract).
- Line length is 30-50 characters and spaces.
- High contrast between type and paper.

**Adequate:** 3 to 4 of above factors present.

**Not suitable:** 2 or fewer of the above factors present, and/or the material looks crowded, cluttered, dense or discouragingly hard to read.

**Variable 14: Layout & Organization**

**Superior:** Throughout material, 5 to 6 of the following factors are present:
- Text type in uppercase & lowercase serif (can use sans-serif in headings of ≤ 5 words).
- Type size ≥ 12 point; no narrow fonts.
- No ALL CAPS for headers or running text (may be done in headings of ≤ 5 words).
- No more than 2 changes in font/text type.
- No ghosted or shadowed text.
- Right margin is left jagged.

**Adequate:** 3 to 4 of the above factors are present.

**Not suitable:** 2 or fewer of the above factors present.

**Variable 15: Typography**

**Superior:** Throughout the text 3 to 4 of the following factors found:
- Advance organizers (headings, subheadings: set/clarify context for content, id relationships among text’s concepts).
- Lists or info are grouped under descriptive subheadings or “chunks”.
- No more than 5 items in a list are presented without another subheading or “chunk”.
- Sentences/paragraphs linked in logical relation or through words such as nevertheless, because, however, therefore, although, since, thus.

**Adequate:** 2 of the above factors are found.

**Not suitable:** 1 or none of the above factors found in the text.

**Variable 16: Subheading or Advance Organizers**

(Even remember more than 5-7 points)

(If not an educational material where this factor is relevant, like newspaper article, mark as NA)

Applies primarily to Health Education material, not, for example, newspapers.

(If newspaper in electronic format, mark as NA)
<table>
<thead>
<tr>
<th>Evaluation Criteria</th>
<th>Factor to be Rated</th>
<th>Score</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning Stimulation &amp; Motivation</td>
<td>6. Learning Stimulation/ Motivation</td>
<td></td>
<td>□ Use of external/implicit request to pay attention (see example ➔) □ Unusual way of presenting content, like comics or photo-novella □ Consistent use of verbal immediacy: ➔ Your ob-gyn rather than the physician □ Use this, these and here (Not: that, those, and there) □ Use present tense (this is your brain on drugs) Adequate: Text contains 1 of the above. Not suitable: Overall, text uses none (0) of the above motivators.</td>
</tr>
<tr>
<td>Superior: Material contains 2 or more of the following to motivate reading/attention:</td>
<td></td>
<td></td>
<td>Examples of limited relevance/inclusivity: □ Schedule a Pap test after 5:00 (work hours). □ Talk to your boyfriend about HPV. □ Tell the doctor you want a second opinion. Examples of inclusivity: □ Schedule your Pap test at a time convenient for you. □ Talk to your partner(s) about HPV. □ In the U.S., it is OK for you to get a second opinion, and sometimes it is encouraged.</td>
</tr>
<tr>
<td>□ Uses language common and relevant to a broad audience rather than a limited one (unless material is targeted to a specific audience) (see examples ➔)</td>
<td></td>
<td></td>
<td>□ Uses visuals that show variety of cultures, genders, ethnicities, ages, incomes, etc. in positive manner □ Attempts to address cultural beliefs, logic and experience when needed or appropriate; presents culture/ethnicity positively and/or validates cultural values. Adequate: Significant match in 1 of the above. Not Suitable: None (0) of the material appears to be inclusive in nature.</td>
</tr>
<tr>
<td>□ Provides examples of info/questions for reader to tell/ask (as of doctor); encourage to write own questions</td>
<td></td>
<td></td>
<td>□ Asks reader to compare/contrast visuals (before/after) □ Present cases and have reader pick best solution □ Use story to convey message □ Have reader complete a story □ Have things reader can cut out (coupons) Adequate: Material uses only 1 of the above, OR a question/answer technique in which answers already given. (Example: headings are questions, and section answers question) Not suitable: No interaction techniques used.</td>
</tr>
</tbody>
</table>

©University of New Mexico Health Evaluation & Research Office (505) 272-1601
Revised August 14, 2006
### Superior: Use of theory/theories evident in text.

**Theory(ies) used:** _____________________

- *All constructs of above theory must be present for superior rating.*
  
**Adequate:** Some constructs of above theory/ies present.

**Not suitable:** No evidence of theory use found.

### Variable 20: Theoretical Application

- [ ] Constructs of above theory(ies) in text include:
  - o
  - o
  - o
  - o

### Superior: Both of the following factors found:

- [ ] Text/ messages framed/stated in positive manner with an encouraging tone.
- [ ] Focus is on solutions reader can take (not just the problem).

**Adequate:** 1 of the superior factors is present.

**Not suitable:** 0 of the superior factors exists. Few to no solutions offered; **tone neutral**.

### Variable 21: Tone

- [ ] If tone not generally used in material category—such as newspaper articles—mark as NA. (Note that newspaper op eds will have a tone.)

### Variable 22: Persuasion Techniques

- [ ] (From media literacy) If materials appear to have absolutely no persuasive or encouragement purpose (application form, insurance card, newspaper article), mark NA.

## Comprehension Categories

<table>
<thead>
<tr>
<th>Comprehension Categories</th>
<th>Total Items, Total Possible Score</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Content</td>
<td>4 items, 8 points</td>
<td></td>
</tr>
<tr>
<td>2. Literacy Demand</td>
<td>5 items, 10 points</td>
<td></td>
</tr>
<tr>
<td>3. Numeracy</td>
<td>2 items, 4 points</td>
<td></td>
</tr>
<tr>
<td>4. Graphic Material</td>
<td>2 items, 4 points</td>
<td></td>
</tr>
<tr>
<td>5. Layout and Typography</td>
<td>3 items, 6 points</td>
<td></td>
</tr>
<tr>
<td>6. Learning, Stimulation, Motivation</td>
<td>6 items, 12 points</td>
<td></td>
</tr>
<tr>
<td><strong>Total SAM+CAM Score</strong></td>
<td><strong>Total Possible Score</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Percent Score</strong></td>
<td><strong>Superior &gt;= 70%</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Adequate = 40-69%</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Not Suitable = 0-39%</strong></td>
<td></td>
</tr>
</tbody>
</table>
SUPPLIES:

- Tape recorder with tapes and extra batteries
- Name tags
- Large pad of newsprint, markers, and masking tape
- Copies of the BMI letter and educational materials (enough for all participants)
- Sign up list with names of participants and contact information, etc
- Guidelines for the Day (large poster sized)
- Body size drawings
- Index cards with words/phrases
- NVS (brought from UMass)
- Pens
- Bottled water, fruit, energy bars
- $20 Big Y gift coupons
- Gift coupon receipts (log sheet from Brenda) (brought from Baystate)

NOTES TO FACILITATOR:

- **AHEAD OF TIME**: Have each of the following ready as people come in:
  - Post the Focus Group Guidelines, either on a wall or a board.
  - Set up the snacks and water for the participants.

- Invite participants to put on name tags (first names only).

- Pause after each sentence or two. This is a lot of information!

- Wait for people to respond before you offer the probes. First reactions are the most important.
A. Purpose.

- Thank you very much for coming today.

- My name is _____ , and this is _____ . We’re from the University of Massachusetts (and/or Baystate Medical Center) and we’re working on a project about the ways people talk about weight.

- We’re interested in hearing about four main things: 1) past experiences you have had talking with health professionals, family or friends about the weight of your child, 2) places you get information about weight and how they make you feel, and 3) the ways you feel about different words used to describe weight, and 4) ways you think about weight.

- The information you give us today will help us learn how to talk with people in a more useful and respectful way about weight. It will also help us make recommendations to the Department of Public Health for the materials being sent home from schools about children’s weight status.

- You’ll probably notice that I will be reading from a “script.” I just use this to make sure I remember to say everything I want to say.


[NOTE: Hand out nametags if they didn’t get one when they walked in.] I’m going to hand out some nametags and markers. Please write your first name and last initial on your nametag.

- Let’s start with a quick ice-breaker. Please tell us your first name only, and a favorite food your child likes to eat in the morning. [NOTE: You can start with yourself to get things going-what you liked to eat as a child]

B. “Our Guidelines for the Day.” [NOTE: To be posted on a wall or board.]

I’d like to take a minute to explain how things will work today. The most important thing is that we want to hear all of your honest thoughts and ideas, so there are a few things that we have to do to make sure this happens.

- First of all, I want you to feel comfortable saying whatever you think. There are no right or wrong answers to the questions. I will respect whatever you have to say, and I’m going to ask that you respect everyone else’s opinions as well.
• **We are interested in what everyone has to say**, so please talk one at a time.

• **Just as a reminder, we are recording our discussion today** so we don’t miss anything you have to say. So please avoid moving papers or talking with others when someone else is talking.

• **Please turn off cell phones.**

• **Your participation in this discussion group is voluntary.** That means you can choose not to answer a question or you can leave at any time without any negative effect on your association or your child’s association with the MIGHTY program, the Springfield YMCA, or Baystate.

• **We’re taking every precaution to maintain the confidentiality of our data**, so please respect the privacy of your fellow participants and do not repeat what is said here to others.

• If you don’t understand a question, feel free to ask us to repeat it or to explain it.

• **This group discussion will take about an hour.**

---

**START TAPE RECORDER: COUNT TO 10!!!!**

**STATE THE DATE, TIME, AND LOCATION OF THE FOCUS GROUP**

**NOTE: ASK ONLY 1 QUESTION AT A TIME AND GIVE PEOPLE ENOUGH TIME TO RESPOND TO EACH QUESTION.**
Let’s start by looking at these drawings of children. Kids come in all shapes, sizes, colors, and personalities, and all that is great. We find that we often associate different words with different body shapes.

- What words would you use to describe the children in these drawings?  
  [NOTE: After the first answer, ask them to specify gender and letter.]
- Look in particular at the children marked E, F, and G.
- If the words you’re thinking of describe one child in particular, please specify the letter beside that child – E, F, or G.

[NOTE: if you get a variety of answers above, you can skip this next part.]

• Now think for a minute about your friends’ children.
  - If you had a friend who had a child who looked like they were toward the right side of this scale (say, F, or G), and you had to talk to your friend about their child’s body size or weight,
  - What could you say that would be sensitive and respectful?
Now let’s talk about HEALTH PROFESSIONALS who have talked with you about your child’s weight. These people can include doctors, nurses, nutritionists, or other health professionals.

[NOTE: Can remind them that they were referred to this program and may have had a conversation with a doctor then, if they are having trouble thinking of an encounter.]

• What negative experiences have you or your child had, when it didn’t feel good to you when a health professional talked to you about your child’s weight?

[Allow 1-2 minutes for discussion; then use the following as prompts:]

Besides what has already been said, have any of you or your children:

- been offended or hurt by what a health professional said about your child’s weight?

- felt like the health professional didn’t understand you or what you or your child have to deal with in your life?

- felt overwhelmed, like dealing with your child’s weight is much more difficult than they think?

- felt confused because they used words you didn’t understand and they didn’t explain things clearly?

[If some participants nod, you can say: “I see some of you nodding. Tell me more about your experiences.”]

[Allow 1-2 minutes for discussion.]

• What kinds of words have health professionals used when talking about your child’s weight that were offensive, hurtful, or confusing, or made you or your child feel these ways?
• Now let’s talk about positive experiences. What positive or good experiences have you or your child had with a health professional, when they talked to you about your child’s weight in a way that made you feel good?

[Allow 1-2 minutes for discussion; then use the following as prompts:]

Besides what has already been said, have any of you or your children:

○ felt respected or supported by what the health professional said?

○ felt like the professional did understand you and your child and what you have to deal with in your life (maybe the health professional asked you or your child questions to try to understand what you were going through)?

○ understood what the health professional was telling you because they spoke clearly and let you or your child ask questions?

○ felt like you and your child could make some changes that would make a real difference?

[Allow 1-2 minutes for discussion.]

• What kinds of words have health professionals used, that helped you and your child feel respected and supported, or sure that you understood, or could make some changes in your life?

THIS IS ALL REALLY HELPFUL!
We’ve just talked about PAST experiences you have had with health professionals who talk about your child’s weight or weight loss. NOW let’s talk about what you would LIKE.

• Imagine a HEALTH PROFESSIONAL needed to talk to you about your child’s weight. What suggestions would you have for them, so they could be most helpful and respectful?

  o What WORDS [or phrases] could they use, that would help you and your child feel comfortable, respected and supported?

  o What information or language would help you feel like you and your child could really make some changes?

[NOTE: If people have trouble answering, say, How would you like a health professional to talk to you about your child’s weight?]
We’re going to be talking a lot about words today. Now I’d like to get your reactions to ten words and phrases that health professionals often use when talking to people about their children’s weight:

• fat
• weight problem
• chubby
• overweight
• obese
• high body mass index (or BMI)
• heavy
• extremely obese
• weight
• unhealthy weight

What other words have you either seen or heard to describe children’s weight, and how do you feel about them? [NOTE: Can ask this in 2 parts]

You're doing great! This is really helpful.
I want to switch gears now and talk about something specific to Massachusetts and a few other states.
In 2009, Massachusetts passed a law that says school nurses are supposed to mail you a letter about your child’s weight when they are in 1st, 4th, 7th, and 10th grades.

- This is sometimes called the BMI letter. How many of you have received a letter like this in the mail so far? [Count out loud the number of people who raise their hands]

[NOTE: Give each focus group participant a sample letter.]

➢ I’d like each of you to take a copy of this letter. We’ve put in some information for a sample child. Take a moment to look it over.

[NOTE: Spend no longer than one minute. Acknowledge if moving on and not everyone appears finished.]

- We’ll be talking about this letter in more detail in a minute, but for now, I’d like to hear your FIRST reaction to this letter.

[Allow 1-2 minutes for discussion.]

[NOTE: Can probe with, What’s the first thing that came to your mind when reading this?]

➢ Now let’s take a closer look at each section separately.

- Look at the section ABOVE the blue dotted line – the child’s results, the colored bar, and the checkmark that shows this child’s weight category. What is this information telling you?

[NOTE: If they just say, “this child is overweight,” say, “Tell me more about that.”]

- What does the colored bar tell you?

- Look at the section BELOW the blue dotted line.

  - What is this letter asking you to do?

  - What would you do?
Now let’s take a step back and look at the letter as a whole again. What could this letter say that would be helpful? What words or phrases would you suggest?

[NOTE: Can probe with: If you were asked to redesign this letter, what would you do or say?]

Along with this letter comes some educational info when it is mailed. What kinds of information would you want that you would find helpful?

I HAVE JUST A FEW MORE QUESTIONS.

[Go to the Newest Vital Sign.]

SO FAR WE’VE TALKED ABOUT YOUR EXPERIENCES, AND HOW PEOPLE HAVE TALKED WITH YOU ABOUT YOUR CHILD’S WEIGHT.

NOW I’D LIKE TO TALK ABOUT FOOD LABELS.

Next, we’re going to switch gears for a few minutes. What I’d like to do now is a short activity looking at the nutrition label that’s on food packages.

The reason we’re doing this is to find out how easy or hard it is to understand the information on the label.

You should have a copy of a nutrition label activity sheet [hold this up] in front of you. Go ahead and put your name on the top of the activity sheet.

[Wait and check that everyone has written their name.]

You’ll be using the activity sheet to write in your answers to each of my questions. Please don’t say your answers out loud because I want to know what each of you are thinking. There are only 6 questions, so do the best you can. It’s okay if you don’t know the answer to a question. If that happens, you can just leave it blank and we’ll go on to another question.

What are your questions?
OK, please take a look at the nutrition label. You’ll be using this to answer the questions I’ll be asking. As it turns out, **this information is on the back of a container of a pint of ice cream.**

Please write ONLY your ANSWERS to the questions on this piece of paper. You can write them on the numbered lines below the food label.

**Question #1 is:** If you eat the entire container, how many calories will you eat?

Let me repeat that.

Now, for question number 2. **If you are allowed to eat 60 grams of carbohydrate as a snack, how much ice cream could you have?**

[Repeat once.]

OK, Question #3 is a longer one, but I’ll repeat it! Your doctor advises you to **reduce the amount of saturated fat in your diet.** [pause] You usually have 42 g of saturated fat each day, which includes one serving of ice cream. [pause] If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?

[Repeat once.]

We’re half way through!

Now for question number four. **If you usually eat 2500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving of ice cream?**

[Repeat once.]

For question number five, I’d like you to **pretend that you are allergic to the following substances:** Penicillin, peanuts, latex gloves, and bee stings. Is it safe for you to eat this ice cream? Please answer yes or no.

[Repeat once.]

When I have used this activity with other groups before, some people say yes for the previous question and others say no. For the final question, question #6, I only need you to listen if you wrote “no” for question #5. If you wrote “yes,” you can leave number six blank.

**Final question:** **Why isn’t it safe for you to eat the ice cream?**
OK, that’s it for the nutrition label. Thanks very much for helping me with this. Brenda will collect your answer sheets.

***********************

Okay, those are all the questions I have.

Is there anything else that would be helpful for me to know?

Thank you very much! This has been really useful.

TURN OFF THE TAPE RECORDER.

REMEMBER TO GIVE THE PARENTS THEIR GIFT COUPONS AND RECORD IN THE LOG SHEET.
APPENDIX P

SAMPLE BMI LETTER

Dear Parent or Guardian:

Your child, ________________________, was weighed and measured as part of our school’s BMI Screening Program. BMI is a way we can check to see if your child has a healthy weight. The results of the screening compare your child’s height and weight to other children of the same age and sex. The results are given as a “percentile.” Your child’s BMI is only being shared with you. No one else will see these results.

Your child’s results were:

Height: 4 ft. 7 in.               Weight: 90 lbs.                  BMI Percentile: 90

If your child’s BMI is below the 5th percentile he or she may be underweight. If your child’s BMI is above the 85th percentile, he/she may be overweight or obese. If your child is not in the healthy weight range, you should talk with your child’s doctor or nurse. He or she can give you ideas about how to help your children get to a healthy weight.

Your child’s weight category is:

Underweight __________
Normal weight _________
Overweight ✔️__________
Obese ________

You may have talked about your child’s weight with your doctor or nurse before, but you can use these screening results to talk with them again. If your child does not have a regular doctor or does not have health insurance, please contact me.

BMI may not tell the whole story about your child’s weight. Other things can affect your child’s BMI. For example, BMI cannot tell the difference between muscle and fat. An athletic child with a lot of muscle may have a high BMI but not be overweight.

I am including information with this letter to help you learn more about what you can do to make sure your child is healthy. You can also learn more at the Department of Public Health’s website www.mass.gov/massinmotion. If you have any questions, please call me at ______________.

Sincerely,
APPENDIX Q

IRB APPROVAL LETTER

Baystate Medical Center
Review Board

DATE: October 12, 2011
TO: Sarah Goff
FROM: Baystate Health IRB #2
STUDY TITLE: [241917-6] The Massachusetts BMI Letter: How are Parents Responding?
IRB REFERENCE #: BH-11-170
SUBMISSION TYPE: Amendment/Modification
ACTION: APPROVED
APPROVAL DATE: October 12, 2011
EXPIRATION DATE: July 1, 2012
REVIEW TYPE: Expedited Review
PROJECT RISK LEVEL: Minimal Risk

Thank you for your submission of Amendment/Modification materials for this research study. The Baystate Health IRB #2 has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a study design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

The following items were included in this submission:

- Amendment/Modification - Modification to Consent Form (UPDATED: 10/4/2011)
- Consent Form - Consent Form - Changes Highlighted (UPDATED: 10/4/2011)
- Consent Form - Consent Form Changes - Clean (UPDATED: 10/4/2011)

Please remember that informed consent is a process beginning with a description of the study and verification of participant understanding followed by a signed consent form. Informed consent must continue throughout the study via a dialogue between the researcher and the research participant. Federal regulations require that each participant receive a copy of the signed consent form unless this requirement has been waived by the IRB.

Proposed changes to the research must be submitted to the IRB for review and approval prior to implementation, unless such a change is necessary to avoid immediate harm to subjects.

Any Unanticipated Problems Involving Risks to Subjects or Others, Deviations from the approved research, Non-Compliance, and Complaints must be reported to the IRB in accordance with Baystate HRPP policies and procedures. If this study includes ongoing oversight by a Data Safety Monitoring Board (DSMB) or other such committee, reports generated by the DSMB or oversight committee must be submitted to the IRB.

Continuations must be submitted 60 days prior to the expiration date noted above. The federal regulations provide for no grace period. Failure to obtain approval for continuation of your study prior to the expiration date will require discontinuation of all research activities for this study, including enrollment of new subjects.

If you have any questions regarding this approval, please contact the IRB office at (413) 794-4356.

Generated on IRBNet
Dear Parent or Guardian:

This important letter is about the health of Example Student. Please read all of it.

Many children in Arkansas have health problems caused by their weight. Recently, your child's height and weight were measured at school. Height, weight, age, and gender are used to figure body mass index percentile (BMI). A BMI is a screening test that only tells if a person is overweight, at risk for overweight, a healthy weight, or underweight.

If a child is overweight, it is usually because the child has too much body fat. Children who have too much body fat have higher risks of health problems than those who have a healthy weight. Overweight or at risk children are more likely to become overweight or obese adults. Obesity may lead to diabetes, high blood pressure, heart disease, and many other problems. Children who are underweight may also have health problems.

Rarely, a child's BMI may be high (at risk for overweight or overweight) because the child is very muscular. Being muscular does not increase health problems for children. Only a doctor can tell if a BMI is high because of too much body fat. Occasionally, a medical condition can contribute to a child's weight. Based on the information below, you may want to talk to your child's doctor.

Why was a BMI measurement done by the school?

State law requires your child's school to measure BMI every year and send a report to you. Arkansas schools also screen children to look for problems with hearing and eyesight. Measuring your child's BMI is another way to help improve his/her health. Actions taken now may lower the risk of developing serious illnesses as a child gets older. So, it is important to measure BMI every year to see if your child is growing and developing in a healthy way.

Is your child's weight a health problem?

Your child was weighed and measured on DATE. Example was X feet XX inches tall and weighed XX pounds, which gives him/her a BMI that suggests he/she may be OVERWEIGHT.

What should you do?

Because Example has a BMI that suggests he/she may be overweight, you should talk to your child's doctor. Please show this letter to your doctor (Example’s BMI was XX or XX percentile). Your doctor will recheck your child's BMI to make sure the measurements done at school are correct. Your doctor can also discuss healthy diet and activity choices for your child. For example, the American Academy of Pediatrics, a group of doctors who care for children, suggests that your family should:

- Offer healthy snacks like fruits, vegetables and foods low in sugar and salt.
- Drink fewer sodas and more water, low-fat milk or low-calorie drinks.
- Limit television and video time to no more than 2 hours a day.
- Take family walks, bicycle, run or exercise with your child.

Healthy habits start early. Please be aware that diet and physical activity will affect your child's health and life.

Thank you,

EXAMPLE SCHOOL NAME

Please go to www.achi.net (OR) www.healthyarkansas.com for more information.
REFERENCES


perceptions of overweight during early childhood. *Qualitative Health
Research, 18*(11), 1548-1555. doi:10.1177/1049732308325537

Goodman, E., Hinden, B. R., & Khandelwal, S. (2000). Accuracy of teen and
parental reports of obesity and body mass index. *Pediatrics, 106*(1), 52-
58. doi:10.1542/peds.106.1.52

Gray, C. M., Hunt, K., Lorimer, K., Anderson, A. S., Benzeval, M., & Wyke, S.
(2011). Words matter: A qualitative investigation of which weight status
terms are acceptable and motivate weight loss when used by health
2458-11-513

Greiner, K. A., Born, W., Hall, S., Hou, Q., Kimminau, K. S., & Ahluwalia, J. S.
(2008). Discussing weight with obese primary care patients: Physician and
doi:10.1007/s11606-008-0553-9

child’s weight status: Psychological impact of a weight-screening program.


from two unique groups.* (Unpublished undergraduate honors thesis).
University of Massachusetts, Amherst, MA.

evaluate patient literacy skills: A preliminary study. *Journal of Health Care
for the Poor and Underserved, 8*(1), 56-69.

Harris, C. V. and Neal, W. A. (2009). Assessing BMI in West Virginia schools:
Parent perspectives and the influence of context. *Pediatrics, 124*(Suppl 1),
S63-S72. doi:10.1542/peds.2008-3586I

Harris, J. E., Gleason, P. M., Sheean, P. M., Boushey, C., Beto, J. A., &
Bruemmer, B. (2009). An introduction to qualitative research for food and
nutrition professionals. *Journal of the American Dietetic Association,

Hassan, K. & Heptulla, R. A. (2010). Glycemic control in pediatric type 1
doi:10.1542/peds.2009-1486


232


