

Children's health information needs and related interventions: a scan of the literature

I. Introduction and background

A. Project overview

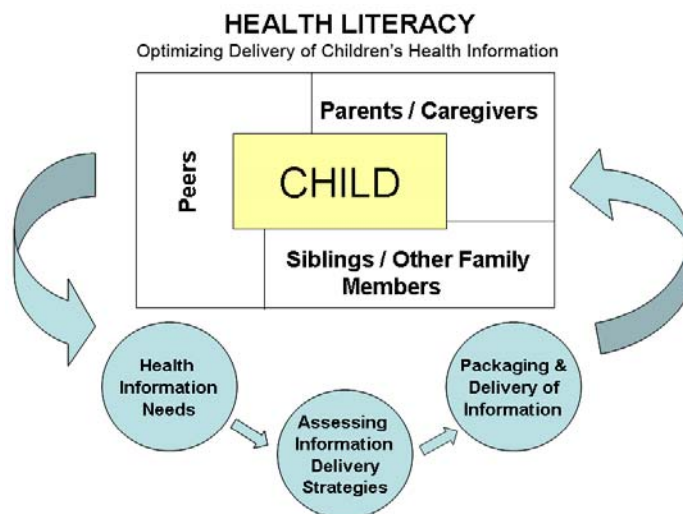
Funded as an Institute of Museum and Library Services (IMLS) National Leadership Grants Collaborative Planning initiative, the *Planning Multidisciplinary and Multicenter Strategies for Understanding Optimal Health Information Delivery to Children* project began in October of 2008. The overall goal of the project focused on developing multidisciplinary and multicenter processes for the investigation of health literacy issues in a pediatric population. To that end, the project's planning process addressed the following aims:

I. Formalizing a diverse expert panel consisting of librarians/informaticians, clinicians, psychologists, educators, and healthcare consumers with expertise in assessing, delivering, and using health information for children; pediatric wellness; engaging the broader community in health interventions; and evaluating the cognitive/learning effects of information to contribute insight into salient research questions and approaches for further investigation.

II. Formalizing key research questions related to the interactions of children with health information, and beginning preliminary development of a research plan and evaluation techniques.

III. Outlining processes and logistics for a future implementation project comprising an initial needs assessment phase followed by an intervention design and evaluation phase.

Figure 1 illustrates the project's general approach.



The team conducted an initial literature review in October-December of 2008 to understand previous information needs research with children and issues of relevance surrounding children's interactions with health information. Such issues included children's, parents', and providers' expectations for health information for children;

children's cognitive abilities; health conditions affecting children; and children's access to health information, especially electronic health information, among others. The following sections address the overall state of the literature regarding particularly salient issues the team uncovered in the literature review and planning process.

B. Research questions

Working with the project's expert panel, the team narrowed the research questions and potential approaches to targeting a pediatric population. Given that little research regarding the information needs of younger children has been conducted, the team elected to focus on examining needs in children aged 5-7 years. This age range is not only inadequately explored in the literature, but, as detailed in the following sections, implementing preventive health interventions among young children may also lead to long term positive effects on health or health knowledge in later years (1). Further, children as young as 4 have been shown to be able to participate meaningfully in their own care for chronic illness like diabetes (2).

To broaden the utility of interventions developed in successive implementation projects, the team also elected to focus on the promotion of healthy behaviors/general preventive healthcare rather than a specific disease or condition. Given that interventions developed will evolve iteratively, incorporating lessons learned from evaluations of material format and content, the team may opt to develop selected disease-specific materials but anticipate an overall focus on general wellness.

Within the parameters of the 5-7 year age group and general focus on healthy behaviors, the team identified the following primary research questions to explore in an implementation project:

- How do children ages 5-7 understand and characterize the concepts of health and healthy behaviors?
- Do children ages 5-7 desire information about health, and if so, how can those needs be characterized and described?
- Do children ages 5-7 prefer particular information formats (e.g. printed materials vs. electronic, narrative/story-based materials vs. "checklists," etc.)?
- What techniques or processes can optimize the presentation/delivery of health information to children ages 5-7?
- How can barriers to the delivery and/or presentation of health information to children in this age group be categorized?
- How can parents' expectations regarding the level and type(s) of health information presented to their children be categorized?
- How can providers' expectations regarding the level and type(s) of health information presented to their 5-7 year old patients be categorized?

Secondary research questions include:

- Does the provision of health information to children in this age range result in social/behavioral, health knowledge, or care-focused changes?
- How can qualitative or other research methods be adapted to elicit meaningful data regarding health information needs from children ages 5-7?

II. Children's health information needs

A. Prior research into children's health information needs

A.1. Health information needs of pre-adolescent children

Children's interactions with health information remains less explored than the health information needs and behaviors of adults (3-14). Houston investigated the information needs of children ages 5-10 with epilepsy, diabetes, and asthma, noting that participants with epilepsy in particular felt they needed more information from their clinicians (15). Smith et al. similarly identified a need for more information in a study of children's preoperative information needs (16), and Hinton assessed needs of children with cystic fibrosis (17). Working with nearly 100 chronically ill and healthy children ages 6-10, Horstman assessed participants' views of the hospital environment and the information children felt they wanted from providers (18). Franck examined inquiries submitted to a United Kingdom health information website written for children and adolescents, noting a surprising number of questions related to understanding hospital procedures and processes from children under 10 (19).

A.2. Adolescent and stakeholder information needs

The literature reflects more thorough investigations of the needs of adolescents relative to cancer: Decker assessed the needs of such adolescents, noting that needs typically fell into the broad categories of information regarding uncertainty, treatment and side effects, social issues, and personal or emotional issues (20). Palmer examined unmet needs in a focus group study of 6 adolescents with cancer (21). Fitch and Kristjanson investigated the information needs of adolescent children of mothers with breast cancer (22;23), and Hokkanen (24), Zebrack (25), and Levenson (26) addressed adolescent cancer patients perceptions of their disease and needs for information. Studies have also addressed adolescents' needs for dental information (27) and needs for general and sexual/reproductive health information (28-34).

Additional research related to health information and children has typically focused on the needs of parents/family or caregivers of chronically ill or developmentally disabled youth (35-55), as well as needs related to well-child care (56). Tetzlaff assessed the needs of parents of children with cancer and developed recommendations for designing informatics systems to best meet parents' requirements (57), while Hu (58) and Hummelinck (59) described the evolving nature of parents' needs depending on a child's disease state (e.g. time since diagnosis). Some research has also addressed the information needs of siblings of children with disease (60-67).

A.3. General information seeking and children

Children's information seeking in general (i.e. not specific to health concerns) has been addressed in several studies; Shenton and Dixon, for example, articulated a typology of children's information needs that includes categories such as "personal information" and "affective support" (68-70). Kuhlthau developed an "information search process" model based on several studies with adolescents and young adults (71;72). Investigators also explored numerous aspects of children's general information behavior (73-75), and Dresang reviewed several "meta-analyses" of studies of digital information seeking by youth (76).

Overall, the literature in the area of children's health information needs generally indicates that children of all ages, particularly children with disease or undergoing a

medical procedure, have a real desire for information. Children facing hospitalization want a clear understanding of what they can expect. Children with disease seek information to explain their conditions and learn how to live with them; they may also be seeking to lessen stigma or “differentness” associated with being ill.

III. Key factors influencing children’s health information needs and interactions

A. Health literacy/numeracy

A. 1. Definition and prevalence

Health literacy is typically 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” (77;78). The prevalence of limited health literacy in the United States has been estimated at roughly 20-26% (79). Health literacy skills are generally grouped into categories of basic/functional literacy, communicative or interactive literacy, and critical literacy (80). Tests designed to measure health literacy typically assess the basic/functional aspect and include the Rapid Estimate of Adult Literacy in Medicine (REALM), Test of Functional Health Literacy (TOFHLA), and Newest Vital Sign (81).

A.2. Effects of limited health literacy

Most investigations of the effects of health literacy on health outcomes were conducted in adults. Though studies have not established causality, several reports identified associations between limited health literacy and poor health outcomes (82-89). Research remains inconclusive, however, and hampered by study design (largely cross-sectional or qualitative studies), differences in measurement, and small study populations (90-93). Health literacy deficiencies may also be associated with increased health care costs (94-96).

Another important aspect of health literacy is health numeracy. The concept of numeracy lacks a formally accepted definition (97-99), but can be thought of as multi-faceted abilities to “understand basic calculations, time and money, measurement, estimation, logic, and perform multistep operations... and to infer what mathematic concepts need to be applied when interpreting specific situations and to use this information to problem solve (100).” Low numeracy skills may limit patients’ comprehension of their disease process and hamper their care (100-104), and numeracy skills are key to patients’ understanding of concepts related to assessing their risk of disease or pros and cons of forms of treatment (98).

A.3. Health literacy in children

Work to assess health literacy in younger populations is limited, with the bulk of studies focused on adolescents and their perceptions of health literacy or health information. There is little, if any, information on the impact of health literacy interventions on children’s and adolescents’ health knowledge and wellness into adulthood (105). Manganello devised a framework for investigating health literacy issues in adolescents (106), and interventions to improve children’s general literacy have been initiated in healthcare settings (107-113). Investigators have also modified health literacy assessments to address adolescents’ abilities (114), and Gray has examined aspects of adolescents information seeking and use of the Internet to locate health information (30;31;115;116). Investigators in Australia employed video creation to attempt to improve adolescents’ health knowledge (117).

Children themselves are also interested in medical information: one in four 9-13 year olds find most health information difficult to understand, yet 41.9% are “very interested” in learning about health; 31% consider parents and 29% medical personnel the first place to go for health information (118). Asthmatic adolescents report an interest in clinician-vetted information on their disease (119).

Some investigators assessed the impact of limited literacy on health-related aspects and learning. Davis et al. examined connections between literacy and violent behavior in children ages 11-18, finding significant associations between reading at below grade level and violent behaviors such as carrying a weapon or engaging in fighting (120). The Joint Committee on National Health Education Standards also developed national health education standards addressing concepts such as promoting children’s understanding of disease and health; contextual/environmental influences on health; and health decision-making skills (121).

Given the relative lack of research into children’s health literacy, developing techniques to assess the concept in younger populations offers a potentially effective means to influence health in later years. Pratt et al. describe childhood and adolescence as “critical windows of opportunity” for teaching health promotion behaviors (1); seizing such openings with young children could positively affect health as children age. This potential grows in importance given the long-term effects of chronic conditions (1;122;123), many of which are increasing among children.

B. Learning in childhood

Multiple philosophical and psychological hypotheses attempt to explain the process of learning in children, along with an understanding of temperament and its relationship to development, personality, and executive attention. Rothbart defines temperament as “individual differences in emotional, motor, and attentional reactivity measured by latency, intensity, and recovery of response and self regulation processes such as effortful control that modulated reactivity” (124).

Children read to have a literacy experience and to acquire and use information and the process of comprehension includes focusing and retrieving explicitly stated information, making straightforward inferences, interpreting and integrating ideas and information, examining and evaluating content, language, and textual elements (125;126).

It is generally accepted that instructional emphasis in kindergarten is placed on play activities, in which students are arranged informally and encouraged to choose activities on which to focus, to promote learning and development. Little time is spent on reading skills such as sound blending and initial consonant stripping but rather on alphabet recognition, sounding out letters, and narrative skills. As the child moves into first grade, more formal instruction occurs with emphasis placed on daily whole-group instruction in alphabet recognition, letter-sound associations, initial consonant stripping, sound blending and addition and subtraction (126).

B.1. The developmental process

Jean Piaget, one of the foremost child development theorists, describes four levels of development (1) infancy, (2) preschool, (3) childhood, and (4) adolescence; each is

characterized by a general cognitive structure that represents the child's understanding of reality during that period (127). Two of these stages encompass the 5-7 year old, and assist with the understanding of developing learning and literacy for this age child.

1. Preoperational stage: from ages 2 to 5 (during this stage magical thinking predominates and there is a focus on the acquisition of motor skills). Egocentrism begins strongly and then weakens. Children cannot converse or use logical thinking.
2. Concrete operational state: from ages 5 to 11 (children begin to think logically but are very concrete in their thinking). Children can now converse and think logically but only with practical aids. They are no longer egocentric.

Piaget provided no concise description of the development process as a whole, though broadly speaking it consisted of a cycle: an action is performed on an object and the child identifies the attributes of the action and its consequences. The action is repeated with some variation until the child recognizes the relationship of cause and effect and can identify characteristics of the object. The repetition of this process enables the child to move to a cognitive stage that allows for dealing with new objects and new knowledge at a higher level. Once a new level of organization, knowledge and insight proves to be effective, it will quickly be generalized to other areas. Each new stage evolves out of the achievement of the old and showcases the importance of sequencing cognitive stages.

Work by Russian psychologist Lev Vygotsky complements this perspective, emphasizing the importance of a child's cultural background as an effect on the stages of development. Because different cultures stress different social interactions, this brought to question Piaget's theory that the hierarchy of learning development had to develop in succession (128). Vygotsky notes there is a difference between what a learner can do with or without help and states often a child follows an adult's example to develop an ability to complete a task alone.

Foorman's work with children revealed they develop best in a classroom with interaction, therefore teachers in elementary schools or pre-school can leverage this to make better use of classroom time using peer interaction (129). Most children respond to what they read through hands-on activities: acting, drawing, mapmaking, storytelling, and writing incorporated heavily into the curriculum, which should ideally be based on the concepts of the five basic types of skills to be developed: motor skills, visual perception, auditory perception, memory perception and social skills. Through the use of shapes, numbers and counting, different games can be played using rhymes, picture sequencing, picture stories, matching, memory, listening, and predicting what happens next. The alphabet can be introduced by saying and writing the letters, both upper and lower case, to emphasize the different shapes and sounds which can be reiterated in the context of storytelling.

B.2. Teaching literacy

B.2.1. 5 year olds

In kindergarten, children can begin work at the word level and continue with the sentence level (125;126). The word level addresses first letters, vowels, two-letter words and rhyming words. At the sentence level, activities can reinforce capital letters, nouns, verbs and sequencing. Making literacy fun can involve many activities such as

reading in the child's environment (stop signs, McDonald's signs etc.), pretending to read by using the pictures on the page, reading books from memory, participating in songs, chimes, chants and poems, making predictions about what might happen next in the story, making up rhyming and nonsense words, and telling similarities and differences between stories.

B.2.2. 6-7 year olds

By six and seven years of age, children are capable of dealing with more complex skills such as phonics and spelling; grammar and punctuation; silent letters; groups of consonants; compound words; suffixes; and comprehension skills (125;126). Interesting ways to continue encouraging children of this age to read include reading easy pattern books, printing out original words from the child and reading them, pointing to recognized words or letters within the story, telling the main parts of the story, making predictions about what might happen next, reading with others and discussing the story, and setting aside dedicated time to reading favorite stories.

B.3. Health education

Health education must ideally begin at the preschool age in order to develop attitudes and competencies about a healthy life and an understanding about which characteristics of everyday activities will help prevent various diseases. St. Leger stresses the importance of incorporating the progress made with literacy into the subject of health education for children aged 5 to 7 years (130). The process of health education begins in early childhood and needs to be oriented to objectives that include knowledge of the structure and working of the human body; knowledge of the risk factors that damage health and how to avoid them; including physical activities and healthy behaviors as part of the daily routine; understanding that good nutrition is the basis of good health; education regarding the detrimental effects of alcohol, drugs, and smoking; and practicing public and personal hygiene. Additional health education topics for children and adolescents recommended by St Leger include: formation of elementary knowledge about the human reproduction; ideas about family and children; how to maintain a healthy heart; elementary knowledge of respiration; and good dental hygiene (130).

C. Childhood health conditions and factors affecting wellness

C.1 Diseases affecting children

National statistics on the health conditions of children in the United States reflect a marked increase in child chronic health conditions over the past several decades (122). The top chronic conditions affecting children today as identified in the current pediatric literature include asthma, obesity, and diabetes.

C.1.1. Asthma

Asthma is currently the leading chronic childhood disease in the United States; 2006 data from the Centers for Disease Control and Prevention estimates that approximately 6.5 million (8.9%) children are affected by asthma (131) which represents more than a 100% increase over prevalence rates reported in 1980 (just under 4%).

While asthma's impact on child health varies with age, the condition maintains a high burden on health care resources such as emergency care and hospitalizations, costs which have risen dramatically in the past decade. The U.S. Centers for Disease Control's (CDC) National Health and Ambulatory Medical Care Survey reports that

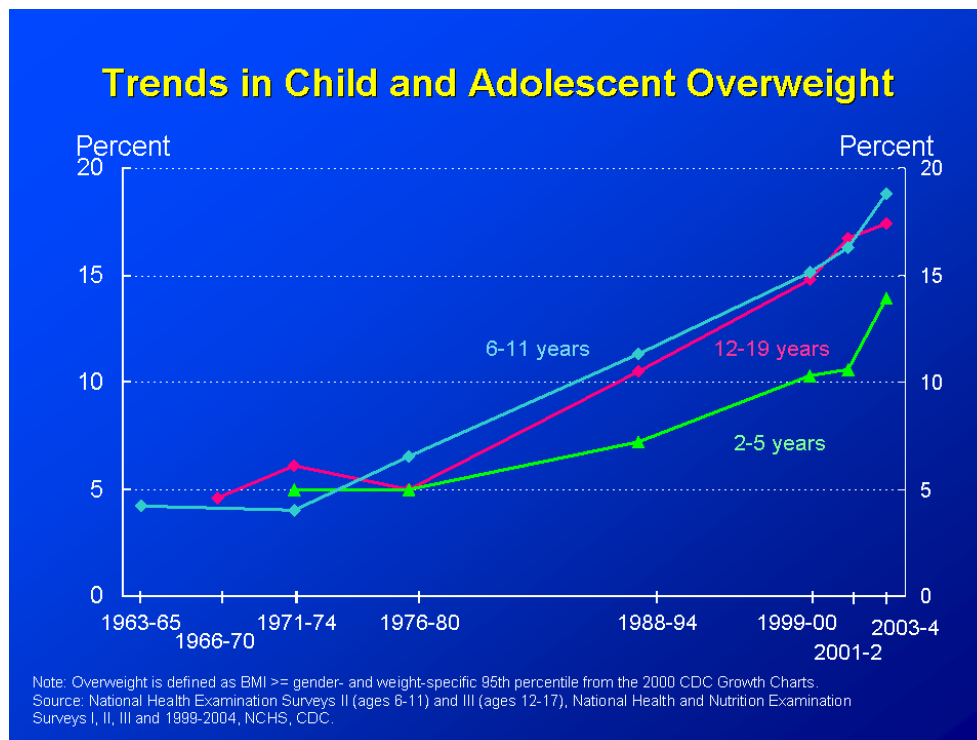
750,000 emergency department visits in 2004 were for pediatric asthma-related care (2.8% of all emergency department visits among children 0-17 years of age) (132). Hospitalization data from the CDC's National Hospital Discharge Survey, which estimates the costs of asthma to the healthcare system and affected families, reports that in 2004 there were 27 hospitalizations per 10,000 (198,000) for asthma (133). This represents about 3% of all hospitalizations among children.

Since asthma attacks are frequently managed in the emergency room, data such as these from the CDC are valuable because they may signal signs of severe asthma, uncontrolled disease, inadequate access to specialist healthcare, or inappropriate use of emergency services. Given its prevalence and high burden of care required throughout children's lives, it is clear why asthma has been included as a priority health outcome for the nation's largest long-term study of environmental and genetic effects on children's health (134).

C.1.2. Overweight/obesity

Another chronic health condition that has been on the rise in the United States in recent years is childhood obesity. Rates of childhood and adolescent overweight status have increased markedly over the past 30 years (135). Like asthma, obesity has also been included as a priority health outcome for the National Children's Study (134) and notably, the American Academy of Pediatrics 2008 list of priorities includes in second place "Thirty minutes of Physical Activity for All School Children in Grades K-12" (136). Data from the CDC's National Health and Nutrition Examination Surveys, as shown in Figure 2, demonstrates the rapid rise in overweight status of children in the United States and supports the need to target physical activity early in childhood (137). The percentage of overweight children increased from 7.2% to 13.9% among 2-5 year olds and from 11% to 19% among 6-11 year olds between 1988-94 and 2003-2004. Among adolescents aged 12-19, the percentage overweight increased from 11% to 17% during the same time period.

Figure 2. Trends in Child and Adolescent Overweight



Researchers also associate obesity with health risks in adulthood. The U.S. Agency for Healthcare Research and Quality (AHRQ) highlights the health burden of being overweight; obese children and adolescents have a greater risk for adult obesity, with its attendant health risks, and may experience obesity-related health conditions before adulthood, including type 2 diabetes mellitus, fatty liver disease, and elevated cardiovascular risk factors (138).

C.1.3. Diabetes

As with asthma and obesity, more children in the United States are developing diabetes at younger ages, making it a third chronic health condition of concern in recent years. Type II diabetes, which is associated with adults (typically diagnosed in adults age 35-40 and older), appears to be on the rise in children and adolescents. Though data on the prevalence of diabetes in children is not as extensively available as for other health conditions, a review of the literature revealed that studies from the 1970s indicated a range from 0.6 to 1.9 cases per 1000 under the age of 19 years old. Results from the most current and comprehensive data from *Search For Diabetes in Youth*, a multi-center study funded by the CDC and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), may shed more light in the future on this chronic health condition in children. The study's goals are to (1) identify the number of children and youth under age 20 who have diabetes, (2) study how Type I diabetes and Type II diabetes differ, including how they differ by age and race/ethnicity, (3) learn more about the complications of diabetes in children and youth, (4) investigate the different types of care and medical treatment that these children and youth receive, and (5) learn more about how diabetes affects the everyday lives of children and youth who have diabetes (139). Thus far, results of more than 3.5 million youth have shown that the crude prevalence of childhood diabetes is estimated at 1.82 cases per 1000 youth (compared with 1.24 of 1000 youth affected by cancer and 120 of 1000 of youth affected by asthma). Study data also reveals that prevalence of childhood diabetes increases with age, females have higher prevalence than males, and non-Hispanic whites have the highest prevalence.

C.2. Children's health in Tennessee

Health measures of children in Tennessee generally reflect national trends and statistics. In a 2003 survey of more than 100,000 Tennessee youth, the overall health status was reported as "excellent or very good" in 85.4% of children aged 0-17 compared to 84.1% nationwide. When parents were asked to rate their child's health status as "moderate or severe", 8.9% of children fell within this category, compared to 7.9% nationally (140).

C.2.1 Asthma in Tennessee

The impact of asthma in Tennessee children mirrors national data. The National Survey of Children's Health reports that 7.5% of children were impacted by their asthma within the past year in Tennessee compared to 8.0% nationally (140). Similarly, the impact of a child's asthma on the family was reported at 15.4% for the state compared to 16.3% nationally. Estimates from the CDC show that between 2001-2005, the prevalence of asthma in the state was between 4.4% – 7.8% for children between the ages of 0-17 (131). Notably, Tennessee's asthma prevalence rates were lower than any of the neighboring southern states.

C.2.2. Obesity/overweight status in Tennessee

In 2005, the Youth Risk Behavior Surveillance System of the CDC assessed health risk behaviors and the prevalence of obesity among youth (141). While Tennessee children exhibit similar levels of television watching and attendance in physical education classes when compared to national data, Tennessee school children from 9th- 12th grade more frequently eat fruits and vegetables less than five times a day (81.7% vs. 78.6%), more often drink soda at least once a day (46.4% vs. 33.8%) and are at greater risk for obesity (16.9% vs. 13.0%) when compared to school students nationwide. In the 2003 National Children's Survey of Health, Tennessee ranked among the lowest for children obesity levels nationwide (44th) and around 35.5% of Tennessee children aged 10-17 are considered overweight or obese for age to body mass index guidelines (140).

C.2.3. Diabetes in Tennessee

Data specific to Tennessee on prevalence of diabetes in youth is typically not as available as information regarding asthma and obesity. National estimates on the growth of diabetes have not been as systematically collected for children. The prevalence rate of diabetes in the Tennessee adult population far exceeds national estimates (7.3% of the state population vs. 9.1% of the population nationally) and the Project Diabetes initiative of the Tennessee Department of Health contains an educational component geared towards high schools in the state (142). The close linkages between diabetes, overweight status, proper eating habits, physical exercise and childhood behaviors make this an area of concern for state legislators and public health practitioners in the state (143).

C.3. Lifestyle and environmental factors that may affect child health

Children have many lifestyle factors that influence the integration of health information. Jackson's research on housing, safe neighborhoods, and transportation concludes that environmental effects have a tremendous impact on the importance children assign health topics (144). If children are concerned about getting enough to eat, then the nutritional value of food isn't going to be highly valued. USA Census data shows that 40% of children younger than 18 come from diverse racial and ethnic backgrounds; 20% Hispanic, 17% African American; and 4% Asian (145). Additionally, in 2004, African American and Mexican American children ages 2-19 had higher rates of overweight than whites (19% and 20% versus 16%). In 2005, more than 28% of US children were living in a single-parent home. Single-mother households carried the highest family poverty rates in 2006, with 28% living lower than the poverty line. Almost 12% of all US children in 2006 had no health insurance (22% of Hispanic children and 14% of African American children).

Academic and non-academic involvement in school and outside of school produces children that are well-rounded individuals. Most children have already been introduced to some type of extracurricular activity by age six, and according to Bergstrom, the problem is finding a balance between school and these activities (146). By age 10, most children are ready for the defined structure and rules that organized sports demand. Although many previous studies have indicated that children who are involved in sports maintain a better grade point average, stay out of trouble and generally have higher self-esteem, that isn't always the case. A recent study conducted by Burton found that in some cases, sports are being linked to drug abuse and aggression in older youths (147). However, the author cautions that other variables – like school setting, coaching styles and parental involvement – also played a role.

Zaff et al. conducted a longitudinal study of students who participated in school-based extracurricular activities consistently from eighth grade through high school and concluded that those students are more engaged in and have a better attitude about learning, perform better academically, enjoy an increased sense of accomplishment, competence, and self-esteem, express more positive involvement in community service and civil involvement, and are more likely to attend college (148). Involvement in extracurricular activities seems to improve time management, social skills, and confidence. Participation also lowers children's risk of becoming depressed, using drugs and alcohol, and experiencing other behavioral problems. Such findings inspired towns and cities across the country to support extracurricular activities by purchasing uniforms, equipment and other supplies. During the past 10 years, the extracurricular establishment has grown into a major cultural force, shaping and defining childhood and family life.

Rosenfield believes that enrolling children in too many activities is a nationwide problem and should be a central focus in current parenting approaches (149), reporting that parents feel they are depriving their children if they're not involved in many activities, and putting pressure on children to achieve and be competitive. Rosenfield and his colleagues organized National Family Night, and encourage Americans to reserve one night a year for family. Brooks, another child expert, echoes Rosenfeld's concerns after interviewing 80 mental health professionals and educators, 60 parents and approximately 100 children (150). Brooks concluded that exposing children to extracurricular activities too early is not necessarily a good idea because some children are not able to function well with so many responsibilities and can develop stress disorders. They have many wonderful opportunities, but no time to call their own or explore things in depth or be creative. When they are involved in too many different things, they sacrifice breadth for depth and squelch creativity.

Eaton stresses there are lifestyle trends that adversely affect children's health such as drinking and smoking at a younger age; body image dissatisfaction and lower self esteem as they relate to unhealthy eating behaviors; and depiction of sexual activities without real life consequences (pregnancy or STDs) (151). Sithole states that sedentary behavior will lead to poor health and an apathetic attitude (152) whereas Powell feels that constant advertisement of high calorie/sugar/fat content food influences children to develop poor eating habits that lead to considerable health issues later in life (153).

Another lifestyle factor that is new to this generation is social networking (154). With the advent of MySpace, Facebook and LiveJournal, children can stay constantly connected to friends -- an activity that can get out of hand and even dangerous. While these new tools may provide valuable avenues for sharing health information, they also present a potential challenge regarding the ease with which mis-information may spread along such social networks.

D. Information and education focused interventions related to child health

D.1. Previous interventions reported in the literature

A literature scan of interventions targeted at health information-related issues in children quickly reveals a myriad of topics related to health and disease in this population. A large number of health information and education-related interventions explored in the

literature included issues related to healthy living, ranging from safety (155-160) to physical activity and nutrition (161-173) to mental health and coping (174-177).

A smaller number of studies focused on educating children regarding health-related issues facing adults; for example, several investigators developed programs for teaching urban elementary school children, many of whom were living with a grandparent as their primary caregiver, about warning signs and appropriate actions to take if they are with an adult who is experiencing a possible stroke (178-180). Morgenstern et al. conducted a randomized controlled trial in an urban area in Texas employing 12 hours of classroom-based instruction plus homework, and found that middle school children receiving the intervention had improved ability to recognize stroke symptoms and increased intent to call 911 when such signs appear in an adult (179). Another interventional study by Williams and Noble implemented among elementary school children in Harlem included interactive mnemonic-based, didactic instruction accompanied by age-targeted music and dance and was associated with improvements in recognition of stroke signs and intent to call 911 in the presence of such symptoms. These improvements diminished somewhat at 3 months post-intervention but some effects persisted (178). Dressman and Hunter found similar results with a stroke related educational program administered to over 500 parochial school children that persisted through 7-10 days post-intervention (180).

A wide range of disease-focused educational interventions are evaluated in the primary literature. Chronic disease topics include a range of conditions, comprising sickle cell, asthma, cancer, obesity, behavioral and mental health issues, and food allergies. In addition, a number of investigators have focused on using information and education strategies to prepare children and their families for surgical and diagnostic procedures. Such projects typically assess and find subjective benefits in terms of comfort and reduction in anxiety related to the procedure, achieved via a range of intervention components including tours, online “virtual” tours and educational materials, coloring and activity books, video, and consultation with healthcare staff dedicated to answering children’s questions about the intervention (181-189).

Interventions including adolescents predominate in the literature. Healthy living topics such as substance abuse prevention and sexual health are fairly well-explored, finding that in-person and online interventions generally succeed in improving adolescents’ awareness of related issues and their intent to practice safe behaviors (190-196). However, information-focused interventions targeted at children also cut a broad swath through the pediatric age groups ranging from preliterate preschool and kindergarten aged children to elementary aged participants (117;162;170;172;197-206). Reports of research projects including the various childhood and adolescent age groups emphasize the importance of considering both chronological age as well as cognitive development in designing, implementing, and evaluating health information interventions, discussed further in the needs assessment section below (see Section III).

D.1.1. Intervention commonalities

Investigators stress the need for involvement of key stakeholders in the design, planning, and implementation of health information interventions in children. In addition to clinicians, these stakeholders may include parents and caregivers as well as teachers, peers, and siblings (207-210). Murray also notes an important associated trend in the more recent research literature in this area. While traditionally children have been

viewed as objects of research in the health information and education literature, current research is evolving to include the child as an active subject and participant in research, an individual who can serve as a key informant in his or her own right (211). Similarly, Alderson et al. note a shift in current medical thinking to view children as partners with adults in their medical decisions and care, rather than just passive recipients of care (2).

Across these studies, investigators emphasize the need for multifaceted interventions for information delivery and health education in children, i.e. using repeated sessions and potentially multiple channels of information delivery (standard care plus an accompanying activity book) (212-217) to reinforce the key “message” of the intervention with participants. Such multifaceted strategies also address another important potential challenge, that of capturing and holding the attention of the child for adequate time to communicate the message of the project (211).

D.1.2. Information design and study setting

As with many information development and evaluation projects, studies also include a pilot testing component to allow for refinement of information delivery format as well as consideration of age-appropriateness of content with children (169;218-222). These pilot studies are intended to devote significant time and effort for designing interventions targeted more closely at children’s learning styles and stage of cognitive development to increase the likelihood of successful achievement of each project’s objectives.

Pilot testing and more formal evaluation of health education strategies in children cover a broad range of considerations (169;218-222), potentially including :

- Child’s understanding/comprehension of the information
- Ability of the content and format to capture and hold the child’s attention
- Effective communication of the “right” information, i.e. the educational objectives that serve as the foundation of the intervention
- Child’s retention of key messages
- Applicability and relevance of the information to the child’s life and behaviors
- Child’s perceived self-efficacy and autonomy related to the topic
- “Actionability” of the information – e.g. delivering specific actions that the child can take to enact change

Researchers also emphasize the importance of avoiding the temptation to provide more information than is necessary or manageable for children; implementation projects focus on developing and delivering a clear and concise message targeted at the issue at hand (59;221;223). Some studies also point to a role for potential peer involvement and reinforcement, such as involving classmates in issues such as diabetes or epilepsy to foster understanding and support of affected students (163;224-227).

The implementation and evaluation research in this area employs designs that reach children and their parents/caregivers in their “native” environments, including:

- Schools (165;224;228-231)
- Activity groups (e.g. Boy Scouts, after school activity programs) (163;166;168;172;218;232)
- Doctor’s office (162;182;233-236)
- Partnering with special meetings/seminars/health fairs for families (174;225)

The literature emphasizes leveraging established venues for information delivery and marketing of information, rather than requiring wholly new connections or settings, such as calling a special seminar at a medical center outside of normal parent and child activities. Thus, researchers attempt to foster participant recruitment and retention by integrating them into the realm of normal activities rather than requiring additional effort or attendance at a novel local meeting.

D.1.3. Information formats

In line with this literature's emphasis on multifaceted strategies for delivery of health-related messages to children and their parents, a broad range of information formats and vehicles for delivering information were evaluated and found useful in the pediatric population. Successful formats for sharing health information with children are varied and include:

- Picture books and workbooks (212-217;237;238)
- Computer and board games (156;167;176;183;231;239-242)
- Skits, puppet shows, theater, songs, dances/activities (167;230;243-245).

Key themes in this area include the importance of incorporating interactive features to engage children's attention, such as including an activity component as a primary delivery mechanism. For example, a small project in Eastern Europe explored an activity involving parents and children to reduce inappropriate antibiotic use; children delivered a skit to illustrate the differences between bacteria and viruses and blew bubbles into the audience to show how such agents spread when one's nose or mouth is not covered during coughing and sneezing (205). Other successful strategies include making the information available in multiple formats and reinforcing key messages for the child via repetition (172;218;246;247). Tying information to visual cues is stressed as particularly important in younger children (182;205;233).

D.1.4. Evaluating health information interventions for children

Prospective approaches are commonly utilized to evaluate health information projects focusing on children, and sample sizes range from several participants for more formative evaluations (163;169;219;220) to several hundred children for larger scale implementations (248-251). Avoiding underpowered studies is a key warning throughout this literature.

Evaluations of health information- and education- related interventions in children employ a number of strategies for assessing the impact of these projects. The technique of pre- and post- test evaluation is a very common approach in this literature; when employing this design, investigators devise a questionnaire related to the health information intervention that may include subjective questions, such as a query about the child's anxiety level related to a health issue, and objective questions, such as a child's knowledge of key health concepts related to the intervention (textbook ref). The pre/post design explores changes in such health-related outcomes associated with exposure to the intervention.

This strategy has been used to explore a number of subjective outcomes related to the child's understanding of the importance of health behaviors; perceived self-efficacy related to a health issue; likelihood of behavioral change; and intent to share information with his/her family (83;161;190; 196; 225;230;252-255). While many studies use self-

report data gathered from the child, some research also collects information on the child's outcomes from the parent(s) or caregiver (256-258).

Though such subjective outcomes predominate, the literature does include some more objective outcomes of health information and education projects. These "harder" outcomes are more often found in interventions that target children with chronic conditions, rather than healthy participants, and may include medication compliance, weight and physical activity monitoring, or adherence to treatment regimens (164;173;246;259;260). Nordfeldt and colleagues, for example, implemented instruction for children with Type I diabetes to prevent severe hypoglycemia; this project included a control group and found that episodes requiring extra contact with caregivers were reduced in the intervention group, while blood glucose levels remained unchanged (261).

D.2. Interventions in Nashville and Tennessee

There are a number of extant programs in Nashville designed to support and share knowledge of health related topics with children. The published medical literature includes an excellent example of one such project in the Nashville area, the formal evaluation of the success of the Drug Abuse Resistance Education (D.A.R.E.) program (262). This program demonstrates a correlation between the impact of the program and preventing smoking among middle school children. Additionally, there are interventions spearheaded by local schools, community organizations, and Vanderbilt Children's Hospital (VCH) to meet the long-term vision and goals for children's health in Middle Tennessee. The United Way of Nashville invests over one million dollars in "Caring for Children" which serves young children in Davidson County and focuses on preparing low-income children to do well by supplying quality preschool programs and providing healthcare training to families who care for medically delicate infants. One of the free services offered through VCH is the "Health Tips" page which provide valuable information on practical ways to keep children healthy, including topics like nutrition, fitness, obesity, first aid and child growth and development.

There are examples of specific interventions conducted through local schools and community organizations that are related to introducing the topic of children's health to the youth of Nashville and the surrounding area (Table 1). Alignment Nashville, a program originating from the Mayor's office, brings together resources that positively impact the Nashville community by helping youth and public school. Another effort, Parent University, is orchestrated by the Metropolitan Nashville Schools and educates parents about care issues including appropriate nutrition, though its primary focus is on graduation rates. Many local and state organizations (Head Start, Tennessee State University, Meharry, Governors Highway Safety and others) focus on child safety, including community efforts related to a variety of projects (e.g. fire, passenger, and bicycling safety).

Other interventions which are achieving success in informing children and parents about health issues are the Children's Advisory Board, with representatives from Governor's office, Mayor's office, VCH, and other organizations, to review health materials for children; and the Coleman Center which develops family-centered interventions regarding nutrition and physical activity. Providing services to underserved populations in the area, the Martha O'Brien Center offers activities for children in the James A. Cayce Homes of east Nashville and started "Tied Together" – a comprehensive

parenting education program that includes nutrition and wellness topics. The local Boys and Girls Clubs conduct the “commit to be fit” program to foster physical activity and social interaction among children and similarly, the YMCA offers afterschool programs to foster child and adolescent physical and emotional fitness. The Giving Matters program complements many of these activities by encouraging over 3,000 non-profit organizations to become a part of the efforts to educate Tennessee children about relevant health issues.

Vanderbilt Children’s Hospital has taken a leading role in the outreach effort for disseminating health information to children in Davidson County and the surrounding area. VCH initiated an information board program featuring the hospital cartoon dog mascot Champ, which shares posters and other education materials with all pediatric offices in state, local health departments as well as the general public. The VCH also funds Public Service Announcements (PSAs) in *Nashville Parent* magazine as well as on *Janet’s Planet*, a Nashville Public Television program. The VCH also works with family literacy programs through Books from Birth, which provides reading materials to children in Tennessee from birth until age 5. VCH’s “Nurses for Newborns” program provides home visits by registered nurses to conduct health-care assessments, education and positive parenting skills to prevent infant mortality and child abuse/neglect. These services are provided to new and pregnant mothers and continue through the child’s second birthday. In addition, VCH organizations distribute information through libraries and daycares; work in tandem with the Health Department and childcare worker associations about nutrition; developed the CASTLE program under the direction of Barbara Clinton at the Center for Health Services to provide an afterschool program that focuses on obesity intervention; direct immunization programs throughout Middle Tennessee, and partner with businesses regarding next generation of workers through Healthy Kids 2025.

These health interventions directed and supported by Nashville community/school organizations and VCH form an excellent foundation for support of improvements in children’s health in Tennessee and provide a rich network of potential collaborators and environments for further developing health education for children and their parents at the local, regional, and state level.

Table 1: Examples of children’s health information and education projects in Nashville and Tennessee

Project	Web Address
Alignment Nashville	http://www.alignmentnashville.org/committees/childrens-health-initiative
Books from Birth	http://www.governorsfoundation.org/aboutus.htm
Children’s Hospital (Vanderbilt)	http://www.vanderbiltchildrens.com/
Coleman Center	http://www.nashville.gov/parks/community/coleman.htm
Commit to Be Fit	http://www.vanderbiltchildrens.com/interior.php?mid=3649
Giving Matters	http://research.givingmatters.com/
Janet’s Planet	http://www.janetsplanetkids.com/janetplanet/
Martha O’Bryan Center	http://www.marthaobryan.org/
Nashville Health Links	http://health.nashville.gov/AtoZ.htm
Nashville Pregnancy and Prevention Programs	http://health.nashville.gov/HAE/hae_AdolescentPregnagy.htm

Nashville Rape Prevention	http://health.nashville.gov/HAE/hae_RapePrevention.htm
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E. Effects of health information on children

The potential effects of such information are also less researched in the literature. Health information provided to children after diagnosis of an illness reduces anxiety or sadness and potentially increases compliance with treatment (263). Information provision before a surgical procedure has been more thoroughly investigated: Justus et al. reviewed literature regarding pre-surgical preparation for children and noted that preparation through various means such as narrative storybooks, interactive play, and pre-surgery hospital tours can reduce children's post-surgical emotional problems and anxiety for parents and children (188). Margolis et al. provided children (ages 2-6 years) with an age appropriate interactive teaching book; children receiving the book were slightly more anxious before surgery but demonstrated fewer post-surgical behavior problems (186). Similarly, significantly more parents of children receiving the book indicated they felt they needed no further preparation information vs. control group parents who received standard preoperative teaching (186). An Austrian study of children ages 2-10 undergoing tonsillectomy and randomized to receive either a child-friendly preparation book and standard teaching or standard teaching alone demonstrated similar results of reduced anxiety in caregivers and children receiving the intervention (189).

In contrast, an earlier study found reduced anxiety in children ages 2-12 resulting from more extensive pre-surgical preparation (i.e. hospital tour + video/demonstration + interaction with a child-life specialist to address questions) only in the immediate preoperative period, though the authors conclude that some level of pre-surgical preparation is useful (187). A study of pre-surgical anxiety among adolescents' reviewing an Internet-based surgical preparation module or receiving standard pre-surgical instruction revealed no differences in adolescent or parent anxiety but greater knowledge acquisition (understanding of the hospital environment, personnel, and equipment) among adolescents viewing the Internet program and greater satisfaction with the Internet preparation method (184).

Health information is also associated with positive effects on children's knowledge of chronic conditions such as asthma and sickle cell anemia. Yoon (222) and Shames (258) used video game-based modalities to provide education about sickle cell and asthma care, respectively, noting increases in knowledge of disease; perceived confidence dealing with disease (222); and perceived quality of life (258). Shames et al. assessed the effects of their intervention on clinical outcomes such as number of wheezing days and uses of a bronchodilator but found no significant effects (258). Similarly, a study of a cystic fibrosis educational intervention, which included health information and targeted teaching, led to improvements in 8-12 year old participants' feelings of loneliness and perceived impact of illness on daily life, but no significant changes in physiologic variables such as pulmonary function (202). Gibson et al. developed a peer led educational program to attempt to improve asthma knowledge among high school students; students in the school participating in the intervention demonstrated increased knowledge of asthma but no changes in quality of life as measured by reported symptoms among students with asthma (264).

Systematic health education, as opposed to simple provision of information, has some effect on health outcomes and costs. For example, in a systematic review of randomized controlled trials of educational interventions directed at asthma self-management in children ages 2-18, Guevara et al. found that “[e]ducational programmes for the self management of asthma in children and adolescents were associated with modest to moderate improvement in many outcome measures, including lung function, self efficacy, absenteeism from school, number of days of restricted activity, number of visits to an emergency department, and possibly nights disturbed by asthma” (265). A study comparing a standard asthma education protocol with the standard protocol plus access to an online interactive asthma game and chat rooms demonstrated significant cost savings from reduced asthma morbidity (197). Finally, a Taiwanese self-management education program aimed at parents of asthmatic children demonstrated an increase in disease knowledge as well as a reduction in medication use and clinic visits in both control and intervention groups (253).

While a number of studies found positive effects of health-related information and education interventions in children, some studies did fail to find a significant difference between intervention and control groups for some outcomes such as anxiety (184;185;187). Furthermore, one study by Margolis et al. found that children aged two to six years who received an interactive educational book before elective surgery showed greater levels of anxiety on the day of surgery as compared with control patients receiving standard care, demonstrating the potential for negative effects of health information in addition to the positive outcomes noted above (186). It is worth noting as well that in this same study, the children who had received the intervention did have fewer behavioral changes at two weeks after surgery as compared with controls, showing positive effects of the intervention following initial negative results (186).

F. Roles of stakeholders in providing health information to children: parents’ expectations for children’s health information

F.1. Overview of the literature regarding parents’ expectations

Parents generally function as advocates and gatekeepers of the information to which children are exposed, a role that may be emphasized for parents of younger children. Literature *directly* addressing parental expectations about providing and controlling health information for their children is sparse and consists largely of qualitative and cross-sectional studies. Extant studies typically discuss the overall needs/expectations of parents of children with specific conditions/diseases (e.g. asthma, head trauma, cystic fibrosis, dermatitis, cancer, diabetes, epilepsy, etc.). Such literature broadly addresses parental expectations regarding healthcare services, emotional support, and information, as well as the specific categories of information sought by these parents. The ages of young people involved in the studies typically range from infancy to 21 years old; however, the majority of studies involve children from 0 to 15 years.

Overall, the findings from the available studies are not generalizable. The parent-child information relationship is highly personal and diverges from situation to situation; such contextual differences incorporate a number of factors that affect the type and level of information desired; the timing of information delivery; and the preferred method(s) in which parents desire the information to be delivered.

F.2. Parental roles related to health information

During patient clinical encounters with health care providers, parents are chief recipients of educational materials related to their child's condition and care (38). Parents consider themselves advocates for their children (266), and as such they want a collaborative approach (parent-clinician) to educating children about disease management (267). They also wish to be an intermediary (between clinician-children) in providing information to the child (59).

F.3. Preferred amount and timing of delivery of health information

In their roles as advocates and intermediaries of information disseminated to their children, parents of hospitalized children feel empowered and less insecure when information needs are met; information acts, in a sense, as a coping mechanism (268;269). Hummelinck found that information gave parents a sense of control and involvement in the child's care plans (59). Also, regardless of their prior education levels, parents of children with juvenile idiopathic arthritis expressed a high level of interest in receiving further traditional and alternative healthcare information on their child's disease (270). Similarly, 88% of parents attending a pediatric outpatient clinic reported that they would like physicians to suggest suitable websites for more information about their child's disease or condition (36). Severity of a child's disease or condition may not dictate the level of information sought; for example, families of children with mild head injury reported the same desire for types and levels of information despite severity of injury (268).

Despite the desire for health information regarding their children's health conditions, parents may sometimes feel unsatisfied with the amount of information delivered; balance is key to effective information dissemination. In Barlow's study of needs related to juvenile arthritis, parent and child participants reported feeling "an enormous gap" between their needs and the information actually received from health professionals, typically leaflets and booklets with factual information about the disease process and hospital attendance versus information addressing wider aspects of arthritis such as the psycho-social impact (38). In a qualitative study of 31 parents of infants with atopic dermatitis, parents typically found the information received from health professionals to be insufficient, and most parents desired written information as backup to verbal explanations (266). In contrast, parents of children with illnesses requiring multidisciplinary care reported feeling information overload at the time of diagnosis versus parents of children with illnesses treated through primary care, who reported insufficient information (59).

Timing of information provided is also a key factor in effective information delivery and potentially just as important as the amount and type of information needed to meet expectations. Perrin and colleagues found that physicians "regularly underestimate parents' apparently insatiable desire for information about their child's condition, particularly when the children's conditions were chronic" (271). However, Rahi and colleagues' survey of parents of children receiving ophthalmic care indicated that the time of greatest parental information needs surrounds the period of diagnosis (272). Similarly, other investigators noted that over time, parents' information needs come to be shaped by "their level of confidence in dealing with their child's condition" (59). Also, parents are generally more capable of absorbing information provided about long-term complications after having dealt with day-to-day disease management (59;267). Thus it may be that a staged approach to the amount and type of information delivered at

diagnosis and throughout the disease management process would serve parental needs more effectively. Francis' study of respiratory tract infection information suggested that providing interactive information booklets designed for use during clinical encounters and training physicians on their use may prompt improved communication between parents and physicians regarding parents' expectations for the encounter (273). Such prompts for communication could occur at any point in the disease management process and help parents obtain information when and where they need it.

F.4. Delivery of negative health information

Delivery of excessive "negative" disease or condition related information, such as that indicating a poor prognosis or ongoing morbidity, could have damaging consequences including increasing anxiety (59). In a study of parents of children with cancer, 97% of 101 participants indicated that they wanted to know "everything" about their child's cancer, but at the same time 31% also indicated that they did not want to "hear about the bad things" (57). Parents also have concerns about sharing negative information with children: parents of children with arthritis were reluctant to give negative information to children to avoid anxiety; however, children reported they did not want to be shielded from negative aspects of their disease and wanted to know "everything," making it easier to cope in the long term with the unpredictable nature of juvenile arthritis (38). Buckloh and colleagues found that parents generally broach negative information with children when disease control is going poorly (267).

F.5. Factors predicting use of/perceived need for health information

Some research investigated factors that may predict the use of and/or the perceived need for health information. Ybarra et al. noted that health information retrieved from the Internet may enhance care; in a national longitudinal survey of Americans ages 12 years and up, 78% of health information seekers reported feeling better about information given by their health care provider because of what they found online (274). Having internet access also logically appears to affect whether parents look for information prior to the clinical encounter: families who searched for online health information regarding the disease or condition prompting a clinic visit were more likely to have Internet access at home than those who had not (78% vs 45%, $p < 0.001$) (36). Tuffrey also found that parents who seek online health information for their children tended to be seeking information regarding multisystem diseases versus less complex conditions (36).

F.6. Personal health records and children

Electronic or personal health records (PHR) are an increasingly important part of healthcare and have the potential to improve patient safety and reign in healthcare costs (275-280). Such systems also raise concerns about control of personal health information and requirements for children (281-285). Frameworks for access to children's personally controlled health records and the level of information available for each user type (e.g. parent, child) need to be further developed and tested. Bourgeois et al. note that PHR systems should be flexible, with varying levels of record access permissions to allow for developmental transitions from childhood to adolescent to adulthood, and propose an incremental transition of access and control to children as they mature (286).

Parents clearly desire effective, actionable health information to address their concerns about their children's health; however, parental expectations related to control of that

information and the level of information provided directly to the child, are areas ripe for further research.

G. Roles of stakeholders in providing health information to children: providers' expectations for children's health information

G.1. Overview of the literature addressing providers' expectations

There does not appear to be a great deal of literature addressing clinicians' expected level of control over the health information or level of disease knowledge provided to pediatric patients. Similarly, the issue of whether clinicians may care differently for informed versus less informed or "avoidant" patients is not well explored; some studies have addressed physicians' attitudes towards "Internet informed" adult patients (287-289), noting some perceived loss of efficiency or challenge to physicians (287;289) and some concerns about misinformation (288). Some literature, especially nursing- and patient education-focused studies, also addresses expected quality elements and clinicians' desiderata for health information for children.

G.2. Providers' quality assessments of health information

Several studies indicate that healthcare providers generally value consumer information that is evidence-based, current, accurate, and presents the patient with multiple treatment options (290-293). A UK study examined whether a febrile convulsion patient education leaflet, revised based on accuracy; the best available evidence; and readability, including the inclusion of illustrations and diagrams, was more effective in increasing parental knowledge compared to the standard hospital fact sheet (294). Similarly, when a pediatric nurse practitioner evaluated written consumer health information on sickle cell disease, criteria for usefulness included content, organization, layout, linguistics, visuals, comprehension and readability (295); the study also found a positive correlation between caregivers' confidence in the healthcare providers and their perceptions of the written material.

In a study by Ens et al., leaders in pediatric palliative care evaluated web-based material for children, noting positive aspects such as support and education for children and negative aspects related to currency, accessibility and monitoring (296). Information delivery methods are also of concern to providers. Belamarich et al. evaluated the quality of health advice directives developed by the American Academy of Pediatrics (AAP), which physicians were expected to deliver verbally to parents/guardians; in addition to finding the amount of information expected to be relayed unrealistic, the directives did not provide evidence that verbally delivery of advice within the setting of the doctor's office improved health outcomes for pediatric patients (297).

G.3. Anticipatory guidance

Providers may also offer health information in anticipation of parents' or patient needs. Such "anticipatory guidance" provides parents/caretakers with information "to help them know: what to expect; how to prevent unwanted conditions or events from occurring; and what to do when an anticipated or unexpected event occurs" (298). Physicians may use well-visit forms as prompts to provide information on various topics such as preventive care or developmental milestones (299;300). Anticipatory guidance is generally associated with greater parent satisfaction and increased well-being for the child and is

often delivered verbally, with written handouts typically used more often by physicians in academic or multi-specialty practices (299).

Anticipatory guidance may offer benefits such as reduced rates of hospital visits and increased parental health knowledge. For example, in a study of HeadStart parents, Herman and Mayer found that improving health knowledge via a self-care manual resulted in reduced emergency room use to treat children's illnesses (301). Similarly, an evidenced-based booklet on managing fevers, developed with input from a health care team, led to greater parental understanding of how to manage a febrile child (302). Simon examined the relationship between anticipatory guidance and injury prevention in children 0-16 months old, comparing the rate of injury visits for families who did not receive injury prevention counseling and those who did; study results suggested that anticipatory guidance reduced injury visits for infants (303). Ear pain management handouts provided during well-child visits also led to a significant reduction in emergency room visits for ear pain (304); additionally, 80% of parents participating in this study indicated that the nursing education helped them avoid an emergency room or after-hours visit.

While clinicians' expectations for the level and type of information provided directly to children are not well explored, these kinds of studies indicate that providers generally see value in educating patients about their conditions. Developing a better understanding of both clinicians' and parents' and children's desires for health information, and thus potentially improving health information materials to better address these needs, could contribute to the healthcare encounter for all parties.

H. Children's access to technology and electronic health information

Many children and adolescents have access to computers and the internet. Among children enrolled in grades K-12, 83.4% use a computer at home, 92.3% use one at school, 63.7% use a computer at home and at school, and 7% do not use a computer at all (305). A 2005 Kaiser Family Foundation report found that 86% of kids 8 to 18 years old have a computer at home, and 74% have internet access (154). A 2001 report on the digital divide found that Tennessee students have a higher rate of computer and internet access at school than students nationally (306).

Children and teens are using those computers to which they have access, and are online. Technology is a major factor in the lives of children aged 12 to 17 – 49% play games online, 63% use a cell phone, 25% use a laptop computer, and 8% use a personal digital device such as a Blackberry or Palm (307). For children 3 to 17 years old, the most common use of a computer at home was to play games (83.1%); other uses of computers included school assignments (66.1%), internet access (64.4%), e-mailing (44.6%), and word processing (45.4%) (305).

Younger children are also using computers; 18% of children 0-6 years old use a computer in a typical day; for 4-6 year olds, 70% have used a computer before, 27% use a computer in a typical day, and 10% use a computer every day (308). Exposure to computers before or during the preschool years has been associated with the development of preschool concepts and cognition among young children (309), but there

does not appear to be a significant relationship between computer use and academic achievement in adolescents (310).

The internet is the primary information source for most adolescents (31), with 50% of 8 to 18 year olds reporting they have looked for health information online (154). Health information topics of interest include sexual and mental health issues, weight loss and gain, and major diseases such as diabetes and cancer (30). Older users (aged 15 to 24) have looked up information on a specific disease such as cancer or diabetes (50%), have searched about pregnancy, birth control, HIV/AIDS or other STDs (44%), and have researched depression or mental illness and problems with drugs or alcohol (23%) (311).

Teenagers (aged 12 to 17) seeking health-related information online report looking for health, dieting, or physical fitness information, with girls (34%), especially ages 15 to 17, more likely than boys (22%) to seek health information online (307). Seventy-five percent of 15 to 24 year olds have searched online for health information; 39% looked for health information at least once a month, 39% have changed their personal behavior based on health information received online, and 69% have discussed online health information with friends (311). There is little, if any, data on health seeking behavior in younger children.

Children and adolescents accessing health information online can be problematic – 70% of 15 to 17 year olds online have accidentally been exposed to pornography and other inappropriate material on the internet, including anti-health messages (e.g., “pro-ana” or pro-anorexia) (311). Filtering software can restrict access to even appropriate health information; among the 76% of this age group seeking health information, 46% have been blocked from non-pornographic sites by filtering software (311). Even if suitable health information can be accessed, spelling errors and medical terminology can affect the ability of young users to find the information they need.

IV. Approaches to assessing children’s health information needs

As noted by Murray, information on children’s information needs were previously sought from parents and teachers, using adults as surrogates in the assessment of children’s perceptions and expectations; however, recent years have led to increasing attention being paid to the child’s right to participate in decisions involving them and gathering reports of needs and perceptions from the children themselves, rather than relying solely on reports by surrogates (211). Growing interest in strategies for collecting data from children has led to the development and adaptation of a number of strategies for assessing information needs in various pediatric populations.

Observational techniques are commonly employed to explore health information behaviors and beliefs in preschool-aged children; gathering data while children are at play is a key strategy employed with this age group (211). As children age, other research techniques become appropriate for health information and education needs assessment; children at the elementary school level may contribute useful data via drawing and focused research interviews, though the literature cautions that children develop at different rates and thus may differ in the quality of their interactions with interviewers (211;312-316). Docherty and Sandelowski’s seminal work provides useful guidance regarding the appropriate structure, duration, and content of interviews involving children, as well as tips for investigators in assessing developmental status and

requirements for children's participation in research (312). Most researchers feel that use of needs assessment techniques similar to those employed in adults (interviews, focus groups, questionnaires, observation) are appropriate for use once children move to the adolescent stage of development (211;315-317).

Irwin and Johnson suggest a number of key considerations for conducting research with children (313); though their tips are focused on interviews involving young children, they are likely more widely applicable in qualitative research involving the pediatric age groups and include:

- Building rapport with the child
- Determining an appropriate structure and length for the interview
- Selecting a setting for the interview which fosters the child's comfort, such as in the home or other familiar location
- Maintaining awareness of the interviewer's own perspective and avoiding leading the child into desired or expected answers, reiterated by Kirk's work (318)
- Being flexible and allowing for the child to shape the interview rather than trying to maintain total control of the interaction.

Research addressing qualitative methods with children typically emphasizes the importance of understanding both chronological age and developmental stage in planning research activities (211;313;314;316-318). In line with a growing focus on the child as a subject of research rather than an object, Kirk's systematic review of methodological and ethical issues stresses several ethical issues related to qualitative research in children, including appropriate protections for privacy and confidentiality; provisions for obtaining parent informed consent and child assent to participating in research; and other issues (318). The literature also stresses the importance of acknowledging differences in developmental stage and age among children, noting that children even within the same age range cannot be viewed as a homogeneous group; this literature emphasizes the heterogeneity of the various pediatric age groups as an important underlying issue through the realm of pediatric health information needs research (211;318-321).

Given awareness of these issues and use of age- and development- appropriate research techniques, the burgeoning field of pediatric health information needs remains a fertile ground for further research with a strong and growing armamentarium of useful techniques for gathering insights into the perceptions and use of information by children and adolescents.

V. Summary

Children's health is a key national and international priority. Strategies for better management of acute and chronic disease, as well as disease prevention and healthy living, are frequent topics of evaluation in the pediatric literature. The published research strongly emphasizes children's desire for information about health and for actively seeking such information. Furthermore, children are increasingly viewed as active participants in their own health and wellness, rather than passive objects to be managed.

Health literacy is also currently a very prominent topic of discussion and debate, with significant impact on health and treatment outcomes in numerous studies. Though

previous explorations into health literacy have predominantly included adults, the limited amount of research into this topic among children indicates that this issue likely has direct relevance to children's health information needs. The extant literature also lacks thorough coverage of specific considerations for assessing and improving health literacy within the pediatric age groups. Though more research is clearly needed to further elucidate the true import of health literacy among children and adolescents, there remains significant interest in understanding the role that information and education play in children's health and disease.

The literature comprises a number of techniques for needs assessment and intervention, as well as established methods for evaluation of such interventions. This literature stresses the importance of involving key stakeholders (e.g. children, parents, other caregivers, teachers, healthcare providers) in the design and implementation of any intervention targeted at improving health among children and adolescents. Technology also provides advances for complementing and potentially replacing traditional strategies for health education in children. Web-based materials (videos, tutorials, FAQs), video games, and social networking tools are all being explored for their potential to augment pediatric health education across a wide range of topics.

While there is a burgeoning body of relevant research, there is certainly much to be learned about the role that health literacy, including both information and education, can play in health and disease among children and adolescents. Library and information professionals with expertise in knowledge management and health outcomes research can serve as collaborators and leverage existing assessment and interventions to further improve understanding of strategies for facilitating children's exploration of health and wellness issues.

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