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Identifying the Preferred Method to Educate Low Income Caregivers About Common Childhood Illnesses: A Step Toward Health Literacy Through a Focus Group Study☆

Mary Jean Ohns, DNP, APRN, CPNP, CCRN *

Toledo Children's Hospital, Emergency Department, OH, United States of America
University of Toledo College of Nursing, OH, United States of America

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ABSTRACT

Purpose: The purpose of this focus group was to identify the preferred method of education for low-income caregivers to learn about common childhood illnesses in an effort to meet their health literacy needs.
Methods: Focus group participants were recruited from two sources; caregivers who qualified for Women, Infants, and Children (WIC) Food and Nutrition Services and those attending a monthly prenatal health education program for low-income pregnant women. Participants were asked to rank in order of preference five educational options. The five options included a commonly used diagnosis-specific handout, a booklet of the most common childhood illnesses and symptoms, a comprehensive book of common childhood illness and symptoms, a 24-hour nurse call line, and a mobile application developed by the American Academy of Pediatrics. All options provided accurate information from professional sources.
Results: The ranking of the five educational options identified the mobile application developed by the American Academy of Pediatrics, KidsDoc, to be the preferred method with the commonly used diagnosis-specific handout as the least favorite option.
Conclusion/practice implications: The United States Department of Health and Human Services (USDHHS) has identified a need to change the way health information is designed and delivered. Identifying that materials should be redesigned using best practices to reduce health literacy demands and match consumer preferences, the USDHHS calls for periodic testing of materials with the intended consumers. This focus group provides valuable information and a step toward future research to address health literacy using materials identified by low-income consumers.

Introduction

The definition of health literacy, adopted by the United States Department of Health and Human Services (USDHHS); is the knowledge, motivation and competency to access, understand, appraise and apply information to form a judgement and make decisions concerning health care, disease prevention, and health promotion in everyday life… (2018). This definition of health literacy incorporates several related constructs that go beyond knowledge, and address the complexity of health literacy (Fig. 1).

According to the USDHHS (2008) only 12% of adults in the United States have proficient health literacy. Those at increased risk of low health literacy skills include adults without a high school education, racial and ethnic minorities, and those with low income levels and public insurance; although, even high school and college graduates can have limited health literacy skills (USDHHS, 2008). Healthy People 2020 has developed a National Action Plan to Improve Health Literacy, based on the principles that everyone has the right to health information that helps them make informed decisions and that services should be delivered in ways that are easy to understand and beneficial to health and quality of life (USDHHS, 2010).

One of the negative consequences of low health literacy among caregivers is non-urgent emergency department (ED) visits. Non-urgent ED visits by pediatric patients comprise 69% to 85% of all pediatric ED visits (Blackburn et al., 2013; Cohen et al., 2013). The demographic profile of caregivers who present to the ED for non-urgent care include those with public insurance, an identified primary care provider (PCP) for their child, and low health literacy (Kubicek et al., 2012; McDermott, Stocks, & Freeman, 2018; Morrison, Schapira, Gorelick, Hoffman, & Brousseau, 2014). Between 2007 and 2015, the number of ED visits

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* Toledo Children's Hospital, Emergency Department, 2142 North Cove Bld., Toledo, OH 43606, United States of America.
E-mail addresses: Mary.ohns@promedica.org, Mary.ohns@utoledo.edu.

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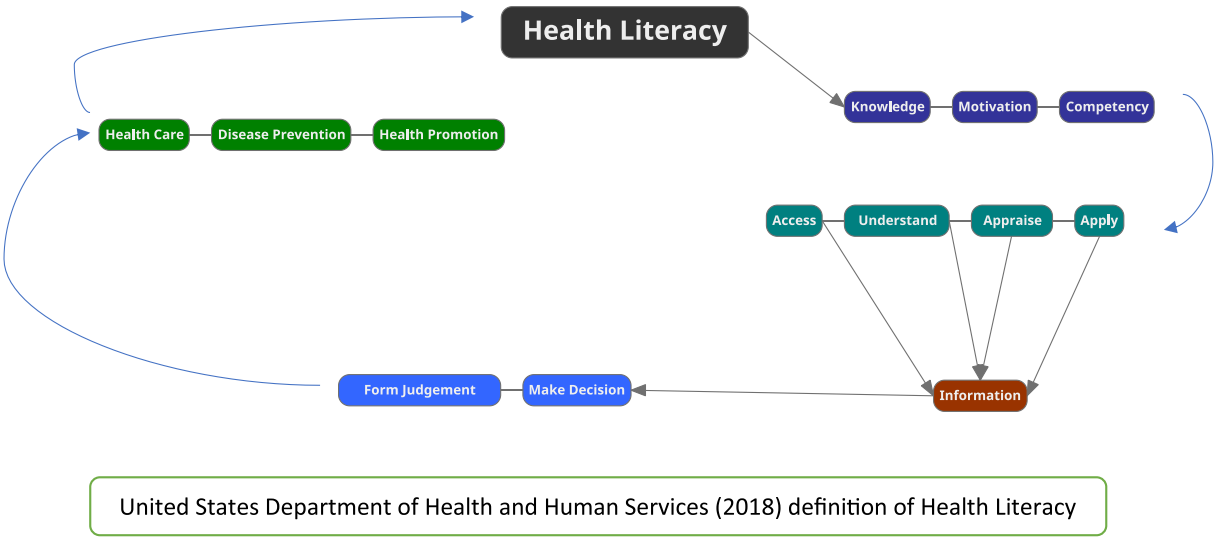

Fig. 1. Constructs of health literacy.

covered by Medicaid increased by more than 50% (McDermott et al., 2018). Morrison et al. (2014) state that caregivers with low health literacy have more than three times greater odds of presenting to the ED for a non-urgent issue compared to caregivers with adequate health literacy. The most common reasons for non-urgent ED visits are acute upper respiratory infections and fevers (CDC, 2015; Cohen et al., 2013). Some unfavorable consequences of non-urgent ED visits include excessive health care costs, unnecessary testing and treatment, and an inconsistent relationship between patient and primary care provider (Uscher-Pines, Pines, Kellermann, Gillen, & Mehrotra, 2013).

According to Yoffe et al. (2011) a caregiver's decision to seek healthcare in the ED is multi-factorial, with knowledge of the child's condition as possibly the most significant factor. If caregivers lack the ability to determine the severity of their child's symptoms, they are more likely to seek immediate healthcare rather than monitoring their child at home, or making an appointment with their child's PCP (Yoffe et al., 2011). May et al. (2018) studied why parents seek care for acute illnesses in the clinic or the ED and found that parents with low health literacy commonly overestimate the severity of their child's illness and take them to the ED for a diagnosis and treatment plan; rarely starting home treatment for fever or pain. In contrast, parents with adequate health literacy are more likely to use internet and print materials as resources and demonstrate problem-solving to initiate treatment of symptoms at home (May et al., 2018). With the knowledge that health literacy skills influence a caregiver's ability to manage mild illnesses, identifying resources that enhance caregiver ability to assess and manage mild illnesses, and are a good fit with the caregiver's literacy level, should be identified as an intervention to address non-urgent ED visits (Kubicek et al., 2012).

The USDHHS's (2008) efforts addressing accessible health information suggest that materials with reduced health literacy demands not be based solely on a reading level, but be redesigned and periodically tested to identify consumer preferences. Sorensen (2018) suggests a people-centered approach to address health literacy by meeting people where they are and empowering them to be active consumers of health care rather than passive recipients of services. The USDHHS (2008) states that health literacy is a process that requires changing the way health information is designed and delivered. The National Action Plan to Improve Health Literacy formulated by USDHHS (2008) calls for the development, implementation, and evaluation of interventions to meet health literacy needs and the dissemination of evidence based practices and interventions. These holistic approaches to meet health literacy needs, demonstrate an integration of the health literacy constructs and are not solely based on providing knowledge at a designated reading level.

With the identification of the high-risk population that uses the ED for non-urgent care (those with public insurance, an identified PCP for their child, and low health literacy) and the understanding that health literacy is a complex concept comprised of related constructs, a focus group was designed. Realizing that in order to address health literacy with a low-income population, identifying educational options that meet their health literacy needs is essential to finding effective interventions to address the multi-factorial issue of non-urgent ED use.

Methodology

Study design and setting

This focus group is the first step in a two-part study to determine the impact of an educational intervention on non-urgent ED use. The purpose of the focus group was to identify the preferred method of education regarding common childhood illnesses among low-income caregivers in an effort to address several of the constructs of health literacy. The subsequent step is to study the impact the preferred method of education has on non-urgent ED visits. Subjects were recruited from two sources; those who qualified for Women, Infants, and Children (WIC) Food and Nutrition Services and those attending a monthly prenatal health education program for low-income pregnant women and their partners. The focus groups were conducted in an urban health care center during May, June, and July 2017. The participants were compensated for their participation with a gift card.

Five educational options were described and presented to the focus group participants. Participants were then asked to rank the five methods of education from one to five. They were also asked to discuss their reasons for the rankings. Comments were audio recorded for review after the group sessions. At the end of the session, participants completed The Newest Vital Sign (NVS), a health literacy screening tool that ranks this concept on a scale from zero to six. The NVS is a screening tool developed to assess for literacy in primary health care settings, focusing primarily on reading and numeracy skills. Health literacy has been defined by the authors of this tool as the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions. The NVS consists of a nutrition label and six questions. Responses to the questions are marked as correct or incorrect according to a predetermined key with greater correct responses indicating greater health literacy. According to the authors of this

instrument patients with more than four correct responses are unlikely to have low literacy. The internal consistency of the English version of NVS (NVS-E) was reported to be acceptable (Cronbach = 0.76 (Weiss et al., 2005). The NVS-E also demonstrated a high degree of concurrent validity with the Test of Functional Health Literacy in Adults (TOFHLA) at 0.88.

Ethical considerations

The study was approved by the institutional review board affiliated with the health care center where the focus groups were conducted. Participants completed an informed consent form.

Participants

A purposive sample of 30 individuals participated in the focus groups. There were eight subjects expecting their first child and 22 with at least one child. Participants were informed of the study by the primary investigator (PI) and voluntarily agreed to participate in the focus group. Inclusion criteria were individuals with low income and at least one child 10 years of age or younger or those expecting their first child. Exclusion criterion was having children older than 10 years of age.

Procedure and data collection

A paper form listing the five educational options was handed to each participant. The PI briefly described each of the five educational options and then passed each option around the group for their review. The purpose of each educational option is to help caregivers manage common childhood illnesses at home and determine when additional care is needed. The PI answered questions as asked by the groups and instructed participants to rank the five options from one to five; with one being their favorite and five being their least favorite on the form provided. The five educational options are further described in Table 1 and included: My Child is Sick!, Caring for Your Sick Child Managing Common Infections at Home, 24-hour Nurse Call Line, Patient Education Print Out specific to diagnosis, and Kids Doc a mobile application. All options are designed for caregivers and provide sound medical information. The Newest Vital Sign literacy screening tool (Weiss et al., 2005) was completed verbally with each participant. The screening tool questions were read by the PI, or a research assistant, individually with each participant and a score from zero to six was documented for each participant.

Following ranking the educational options and completing the NVS-E, subjects were asked to reply to the question, "Tell me why you ranked the educational options the way you did by explaining why you preferred your number one choice and why you did not prefer your number five choice." The responses to this question were recorded on audio tape with the investigator taking supplemental field notes. This question was asked both in the group setting and one on one with participants. Using a phenomenological approach, the PI reviewed the audiotapes and written notes and generated themes about why the sample ranked the educational options as they did.

Results

Demographics

Focus group demographics are described in Table 2. Thirty parents participated in the focus groups. The age range of participants was 19 years to 41 years with 30 years of age as the mean. The number of children per participant ranged from one to five with 2.5 children as the mean and a total of 56 children with 8 participants expecting their first child. Children's ages ranged from newborn to 10 years of age. Twenty-five participates reported having public insurance, two participates reported private insurance, and three participants did not answer. Education of the participants ranged from some high school ($n = 5$), high school graduate ($n = 11$), some college ($n = 9$), college graduate ($n = 3$), did not answer ($n = 2$).

Literacy scores

Literacy scores ranged from zero to six with the mean score of 3.57 and a standard deviation of 1.48. The literacy scores are interpreted as follows: 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 (Weiss et al., 2005). The average literacy score for participants with a high school education or less ($n = 16$) was 3.12, while the average literacy score for participants with some college or a college degree ($n = 12$) was 4.17. With a mean literacy scores of 3.57, the group overall demonstrated borderline limited reading and numeracy literacy skills. See Table 3 for literacy scores and Table 4 for literacy scores and education.

Preferred educational method

The five educational options were ranked from one, the focus groups' preferred method of education; to five, the focus groups' least

Table 1
Educational options.

Title	Author	Description	Pages	Cost to Parent
My Child is Sick!	Barton Schmitt, MD, FAAP American Academy of Pediatrics	Offering fast answers to questions about 50 common ailments and symptoms, this handbook provides clear guidance on when it would be acceptable to treat symptoms at home and when emergency care is required	426	$16.95
Caring for Your Sick Child Managing Common Infections at Home	Barton Schmitt, MD, FAAP American Academy of Pediatrics	Written at a sixth-grade reading level, this brochure covers the most common infections and symptoms of childhood, and informs parents when an illness warrants a trip to the doctor or emergency room - and when an illness can be safely treated at home	24	$4.99 purchased through AAP
24 Hour Nurse Call Line	Pediatric Telephone Protocols authored by Barton Schmitt, MD, FAAP and endorsed by American Academy of Pediatrics	24 h a day, 7 days a week phone access to a RN who can answer questions and give advice. Free of charge; service of Medicaid insurance provider		Covered by insurance
Patient Education Print Out specific to diagnosis	Various	Software programs used in primary care practices. Key words related to the diagnosis are searched and standardized education is available. Provider is able to add additional individualized instructions	Varies ~2–8	Covered by insurance
Kids Doc Mobile application	American Academy of Pediatrics	A mobile application designed especially for parents to help them make smart decisions on what level of care (if any) is needed and how to provide speedy symptom relief for minor illnesses or injuries that can be managed at home		$1.99 available on Apple and Android phones

Table 2
Demographics of focus groups.

Characteristics	
Age	
Range	19–41
Mean	30
SD	5.7
Education	
<High School	5
High School graduate	11
Some college	9
College graduate	1
Foreign graduate	2
Did not answer	2
Insurance	
Medicaid	25
Private	2
Did not answer	3
Number of Children	56
Range	1–5
Mean	2.5
Pregnant with first	8
Age of Children	Newborn to 10 years
Literacy Score	
Range	0–6
Mean	3.57
SD	1.48

favorite educational option. The preferred method of education identified by the focus groups was the mobile application, Kids Doc, created by the American Academy of Pediatrics. Second, was the 24-hour Nurse Call Line; third was the book, My Child is Sick! Fourth was the booklet, Caring for Your Sick Child Managing Common Infections at Home; and fifth was the Patient Education Print Out specific to diagnosis. Of note, 25 of the 30 caregivers ranked the Patient Education Print Out as their 4th ($n = 8$) or 5th ($n = 17$) choice.

Even though there was no statistical significance found when comparing literacy scores and preferred method of education (ranking the educational option as their first or second choice), the following associations were noted. Those who ranked the book, My Child is Sick! as their first or second choice had an average literacy score of 3.71. Those who did not prefer My Child is Sick! had a literacy score of 3.38. Those who ranked the mobile application as their first or second choice had a literacy score of 3.42. Those who did not prefer the mobile application had a literacy score of 3.82. (see Table 5 for literacy scores and educational preferences). Another variable, associated with literacy, is education level; however, no association was found between preferred method of education and education level.

Age of the subjects was compared among the three most frequently preferred methods of education consisting of the mobile application, the 24-hour Nurse Line, and the "My Child is Sick!" book. A one-way ANOVA with Tukey post hoc comparisons indicated those who preferred the mobile application were younger (27.6 ± 5.8 years) than those who preferred the 24-hour Nurse Line (34 ± 4.9 years) and those who preferred the "My Child is Sick!" book (30 ± 3 years) ($p = 0.03$).

Table 3
Literacy scores.

Literacy Score	Number with Score
0	1
1	1
2	5
3	7
4	8
5	5
6	3

Mean 3.57; Standard Deviation 1.48.

Table 4
Literacy scores and education.

Education	Literacy Score
High School or less	3.12
Some college or college degree	4.17
Mean 3.57 Standard Deviation 1.48	

Qualitative

The participants shared very few comments regarding the ranking of the educational options and why they ranked the options as they did. The two themes that emerged from the participants' comments were related to *access to information* and *comprehensiveness of information*. The primary reasons for the caregivers' rankings centered around immediate access to information and breadth of information provided. These themes are consistent with the health literacy constructs of access and knowledge. One mother commented that she preferred the mobile application and the Nurse Line because she could use them "wherever I am." She continued "… my kids tend to get sick on vacation" and these resources would always be available. Another mother who preferred the mobile application stated, "they got everything in this app!" A mother, who preferred the Nurse Line, stated she preferred to "call and talk to somebody" she found it to be "more educating."

Comments from caregivers who did not prefer the Patient Education Print Out specific to diagnosis said, "it is lost in my car somewhere," "it's wasted paper," "I throw them away." "it's too vague." Regarding the various literacy demands of the options, one mother stated she had "problems reading" and prefers resources with pictures because she "gets overwhelmed with a lot of words." Another mother stated, "I definitely hate reading books, I would rather look something up on the internet." A mother who chose the My Child is Sick! book as her preferred method stated she liked the amount of information in the book.

Clinical implications

Addressing health literacy of low-income caregivers has numerous benefits. Caregivers with adequate health literacy skills are more likely to make proper health care decisions for their children leading to better health outcomes. As suggested by the USDHHS, health literacy is a process that cannot be accomplished by merely designating a reading grade level for written materials and is defined by several related constructs. Additionally, it does not appear that there is a single educational option that meets the needs of all low-income caregivers. With this in mind, providers should consider offering a variety of educational options that meet a range of literacy and technology skills. Identifying low-income caregiver preferences of educational materials and options is crucial. Of note, the least favorite educational option, the Patient Education Print Out specific to diagnosis, was ranked fourth ($n = 8$) or fifth ($n = 17$) by 25 of the 30 participants (83%). This educational format is commonly used in primary care practices and emergency departments, but if this resource in not meeting the health literacy needs of low-income caregivers, other options should be explored.

Determining which constructs of health literacy are met by the preferred methods of education may be a helpful next step in identifying

Table 5
Literacy score and educational preference.

Mean Literacy Score	My Child is Sick!	Caring for Your Sick Child	24-Hour Nurse Line	Handout	Mobile Application
Not prefer	3.38	3.6	3.62	3.56	3.82
Prefer	3.71	3.4	3.53	3.67	3.42
P-value	0.78	0.87	0.65	0.61	0.43

Mean Literacy Score 3.57.

educational options for further study. If the mobile application (first choice) and the 24-hour Nurse Call Line (second choice) were made available to caregivers, they would have continual access to two educational sources, as long as they had their mobile phones. The 24-hour Nurse Call Line requires the lowest level of reading literacy and caregivers can *discuss* their concerns with a RN. The mobile application, designed for caregivers, is a user-friendly technology option for caregivers to review symptoms and determine appropriate treatment. When considering the constructs of health literacy (Fig. 1) these two educational options have the potential to address eight of the thirteen health literacy constructs. The mobile application provides *access* to *information* and the potential to impart *knowledge, judgement,* and *decision-making* (as the application states when home care vs. a primary care visit vs. an emergency department visit is appropriate). When the 24-hour Nurse Call Line is added, the additional constructs of *appraising, applying and understanding* of information can be facilitated by the phone conversation between caregiver and RN. Combining these two educational resources has the potential to result in caregivers making appropriate *health care decisions*.

While utilizing the results of this focus group to construct interventions that will be effective in addressing non-urgent ED use additional factors need to be considered. First, non-urgent ED use is a multifactorial issue that will not be solved with an educational intervention. Education alone will not address the issue of ED convenience, transportation issues, or caregiver's level of confidence in the child's PCP; however, some of the constructs of health literacy have also been identified as reasons for non-urgent ED use. Access, knowledge, judgement and decision making are constructs of health literacy that can be addressed through educational interventions and have been identified as reasons for non-urgent ED visits (Yoffe et al., 2011). Second, the high-risk population for non-urgent ED use in addition to having low health literacy skills also has low-income, so interventions would need to be cost effective. All individuals with Medicaid insurance, in the state of Ohio, have free access to a 24-hour Nurse Call Line as an insurance benefit, making this option free to the consumer. The mobile application from the American Academy of Pediatrics has a one-time cost of $1.99. Perhaps the PCP or Medicaid would be interested in coving this cost if this intervention was found to be effective in decreasing non-urgent ED use.

The benefits of determining effective educational options that can be implemented with the high-risk population that uses the ED for non-urgent care are numerous. When caregivers seek the appropriate level of health care for their children, health care costs will decrease as a result of fewer ED visits. When care is provided from a single primary source, continuity of care improves and appropriate referrals and follow up can be accomplished. For example, when a child's asthma is managed from a primary source, appropriate daily asthma management can be determined and asthma exacerbations prevented; as opposed to managing asthma solely by treating exacerbations in the ED. Children with a history of urinary tract infections (UTI) are more likely to have the appropriate voiding cystourethrogram (VCUG) follow-up when the number of UTIs is tracked by a single primary provider rather than treating UTIs in the ED. Children with a history of streptococcal pharyngitis are more likely to have a tonsillectomy when they meet criteria based on the number of strep infections, if that number is tracked by a primary provider. Children with a history of recurrent acute otitis media are more likely to have timely tympanostomy tubes placed if the child is diagnosed at a primary site, rather than various EDs or urgent cares (Ohns, Oliver-McNeil, Nantais-Smith, & George, 2016).

Additional areas of concern when children seek care in the ED rather than from a primary care source, is the potential for missed or delayed well visits. This lack of continuity of care can lead to missed or delayed immunizations as well as missed screenings, missed diagnoses, missed opportunities for early referral, missed anticipatory guidance, and missed prevention education. (Ohns et al., 2016).

Future research

The next step in an effort to determine the impact of providing the preferred method(s) of education on health literacy would be to measure an outcome indicative of meeting health literacy needs of caregivers. Providing educational materials that are effective in not only increasing caregivers' abilities to manage common childhood illnesses but that would also help caregivers make timely decisions about the appropriate site for care (ED vs. PCP office vs. home care) would be a valuable research project. While it is known that education alone does not assure adequate health literacy and non-urgent ED use is a multifactorial issue requiring more than a single intervention solution, research using interventions that address the constructs of health literacy and are chosen by the at-risk population have a solid foundation for success.

Author statement

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