

Health Literacy Needs of Family Members & Caregivers of  
Children With Special Health Care Needs

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### Abstract

The purpose of this article is to explore the complex health literacy needs of families who have children with special health care needs (CSHCN). Health literacy is a national and global issue. Neither reading literacy nor higher education is a guarantee of health literacy. Higher health literacy leads to better health outcomes. There is a significant population of our children who have some form of special health care (HC) need. Some estimates suggest between 13-18% of US youth can be classified as CSHCN. Of that population of CSHCN, about 57% have more than one chronic condition. The parents and caregivers of CSHCN need a high level of health literacy and good health communication with providers to provide adequate care to their children.

*Keywords:* children with special health care needs, CSHCN, health literacy

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**Statement of the Problem**

Health literacy (HL) is a national and global issue. Like reading literacy, health literacy will impact almost everyone in some way at some point in their lives (World Health Organization [WHO], 2013, p. iv). However, health literacy is more multifaceted than reading literacy. According to the Affordable Care Act of 2010, health literacy is defined as, “the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services in order to make appropriate health decisions” (p. 1252). This definition was previously used in the Healthy People 2010 guidelines and in *Health Literacy: A Prescription to End Confusion* (Human & Health Resources [HHS], 2010; Nielsen-Bohlman, Panzer, & Kindig, 2004). The authors of *A Prescription* (2004) state, “Health literacy, then, is a shared function of cultural, social, and individual factors” (p. 32). They state further that, “Recognizing the limitations of this definition, the committee [of Healthy People 2010] acknowledges the need for future development of definitions and measures that address the critical role that society, the health system, and the education system play in creating a truly health-literate America.” (Nielsen-Bohlman, et al., 2004, p. 37). While the aforementioned definition is utilized as the national legal standard, there is still no clear consensus on an educational and public health standard definition.

Many individual and institutional researchers have formulated a working definition of HL that conforms to their particular need, field, or profession. Sørensen, et al. (2012) found 17 different definitions of the term “health literacy” (p. 83). Of these definitions, ten refer to a

person's abilities, three refer to a person's capacity, and nine refer to a person's skill set. It can be important to distinguish between capacity/ability versus skills. Capacity and ability both imply a quality that is innate and fixed. Skill signifies an attribute that can be taught and learned and that can change over time. Studies support this fluidity of an individual's health literacy skills. For example, adults over the age of 65 are more likely to have a lower health literacy (Office of Disease Prevention and Health Promotion [ODPHP], 2010, p. 7). As Sørensen, et al. (2012) point out, "Health literacy is also a process, which involves the consecutive steps of accessing, understanding, processing and communicating information" (p. 92). A health-literate person must know how to deal with an increasingly complex medical system and a barrage of health information, medication choices, and health insurance options. The National Action Plan to Improve Health Literacy states, "Health literacy requires knowledge from many topic areas, including the body, healthy behaviors, and the workings of the health system" (ODPHP, 2010, p. 5). It is clear that a person who is health literate must be so much more than a literate reader.

**Scope of Health Literacy Problem.** In the United States, there is an overall low rate of health literacy. Nearly 90% of Americans lack the degree of health literacy needed to get the full benefit of any medical advice they receive (Centers for Disease Control & Prevention [CDC], 2016). Because health literacy involves a different set of skills than reading literacy, even a well-educated person can have a low health literacy. "Directions for operating a particle accelerator, filing income tax returns, or choosing between health insurance plans may be similarly indecipherable for most adults, regardless of literacy skills in other contexts" (Nielsen-Bohlman, et al., 2004, p. 61). Neither reading literacy nor higher education is a guarantee of health literacy. Therefore, health literacy must be viewed and treated as a distinct entity.

### **Children with Special Health Care Needs**

Health literacy is important for all Americans but for those individuals with chronic health problems, health literacy can improve their daily health and long-term health outcome (CDC, 2016). Children with special health care needs (CSHCN) are a vulnerable subset of this population. Special needs can be a nebulous term when it comes to children's health needs; however, a specific definition is required to quantify data. This paper will use the definition for CSHCN from the Maternal and Child Health Bureau, which states, "Children are considered to have a special health care need if, in addition to a chronic medical, behavioral, or developmental condition that has lasted or is expected to last 12 months or longer, they experience either service-related or functional consequences, including the need for or use of prescription medications and/or specialized therapies" (Maternal and Child Health Bureau [MCHB], 2014, para. 1).

**Prevalence of Children with Special Health Care Needs.** The ideal childhood is happy and healthy. However, for many children in the United States, reality is far from this idyllic archetype. Some estimates suggest between 13-18% of US youth can be classified as CSHCN (Keim-Malpass, Letzkus, & Kennedy, 2015, p. 1). While not every child with special health care needs will require intense or prolonged medical care, many will. Further, many CSHCN have comorbid conditions that require the need for multiple pediatric specialties. According to the National Survey of Children with Special Health Care Needs (2009/10), about 57% of CSHCN have more than one chronic condition. For example, a recent study found that up to 95% of children between 4 and 8 years old who are on the autism spectrum had at least one other condition or syndrome (Soke, Maenner, Christensen, Kurzius-Spencer, Schieve, 2018, abstract).

**Impact of CSHCN on Families and Caregivers.** Of course, children do not live alone. They are dependent on family and caregivers for everyday health needs, access to medical care, and the performance of any home-based care. This paper will use the term “family/caregiver” to recognize that many children are now regularly cared for by adults other than their biological parents. Parents/caregivers of children with medically complex conditions must cope with and learn how to navigate the health system and the health insurance quagmire. “Children and youth with special health care needs and their families often need services from multiple systems – health care, public health, education, mental health, and social services” (MCHB, 2016). They must also understand their child’s individual diagnosis or diagnoses, also known as disease-specific knowledge, or DSK (Carden, Newlin, Smith, & Sisler, 2016, p. 122). As with all health consumers, health literacy for these families/caregivers involves so much more than being able to read and write. There is a whole myriad of skills that they must know or learn in order to properly care for their children.

**Impact of Parental Health Literacy on CSHCN.** The low rate of health literacy in the United States impacts families of children with special health care needs disproportionately (\*\*\*) Reasons for this are varied. Children with SHCN have: more complicated health care needs; a greater need for medical care; an increased usage of health care services; an increased need for home-based care; and health care needs that change over time.

Additionally, this extra level of care can have profound impacts on the family unit, from special financial costs related to the child’s health needs, extra time needed off from work, the necessity for one parent to stay home with the child, and the mental and physical burden of caring for a sick child (Dey, Wang, Jorm, & Mohler-Kuo, 2015, p. 409; HHS, 2004). According to the National Survey of Children with Special Health Care Needs of 2009/10, a child’s health

condition/s causes family financial problems in about 22% of families with CSHCN; the percentage of CSHCN whose families spend 11 or more hours a week providing care is around 13%; and finally, the percentage of CSHCN whose conditions cause family members to cut back or stop working is 25% (NS-CSHCN 2009/10).

**Health Literacy Needs of Families/Caregivers of CSHCN.** The complexity and breadth of health literacy demands for these caregivers can often be overwhelming. These demands can include providing home care for a chronically sick child; understanding medical information from a variety of sources; understanding, obtaining and administering medication to the child (often multiple medications); navigating the health care system; navigating the health insurance system; understanding and utilizing federal and local laws and regulations related to their child's legal and educational rights; and finally, communicating with a variety of health care personnel, all of whom have their own specific jargon—doctors, nurses, front desk, OT, PT, speech and audiology, orthotics, mental health care providers, pharmacists, special education teachers, school administrators, and more. Almost 5% of these families have more than one child with SHCN, which compounds the level of burden; this equates to more than 1.5 million families (NS-CSHCN 2009/10).

Wolf, et al. (2009) describe in detail what literacy needs are required for families of CSHCN:

The parent and pediatric patient, in turn, are expected to be able to provide an accurate account of behaviors or symptoms, and both raise and answer pertinent questions within a medical and social history-taking process. Beyond the physician visit, the parent must remember what transpired during the interaction with the physician to make appropriate decisions. In addition to the interpersonal communication, information about

recommended health behaviors, promotion for self-care, treatment decision-making, or even directions for navigating a particular health system are conveyed by using various health technologies. Families are expected to be able to use available communication tools, which may range in complexity from print forms, brochures, and telephone contact to interactive video programs, electronic health record ‘patient portals,’ and the Internet (p.S277).

The health literacy level of parents/caregivers impacts the health outcomes of CSHCN. The life course approach to assessing needs of CSHCN emphasizes the importance of early recognition and treatment. Anderson, et al. (2017) state:

Spending on children’s health is different from that of adults in other important ways. It should be seen as a societal investment rather than simply a cost, in the way that education is, with the benefits accruing over the life course rather than in any enrollment period or fiscal year. The benefits of children, especially CYSHCN [Children and Youth with Special Health Care Needs], entering adulthood in a healthier state has implications not only for individuals but also for society in general (pg. S100).

### **Review of the Literature**

There is a lack of available data related to the parental or caregiver health literacy needs of CSHCN. Keim-Malpass, Letzkus & Kennedy (2015) reviewed the literature about health literacy as it relates to children with special health care needs and their families/caregivers. Their findings point out the lapses in research in this vital area. “There have been comparatively few studies that assess parental/caregiver health literacy of CSHCN, even though they may be at particular risk for inadequate information exchange, confusion regarding complex home



medication regimens and treatment instructions, and non-adherence to medication or recommendations” (Keim-Malpass, Letzkus, & Kennedy, 2015, p. 2).

Although many children with special health care needs have more than one health condition, most studies only look at children with a single disease process, such as asthma or diabetes. Keim-Malpass, et al. (2015) state, “CSHCN often have multiple co-morbid conditions, and none of the included studies involved samples with more than one condition” (p. 9). Many of these studies involve parental health literacy and childhood asthma (Gahndi, et al., 2013; Harrington, Bailey, Zhang, Magruder, & Gerald, 2015; Yin, et al., 2017). Some studies focused on pediatric patients with diabetes (Howe, Cipher, LeFlore, & Lipman, 2015; Pulgañon, et al., 2014).

Carden, Newlin, Smith, & Sisler (2016) studied health literacy and disease-specific knowledge in parents/caregivers of children with sickle cell disease. They suggest that an instrument that tests DSK would be more helpful for families of CSHCN than a general health literacy tool (p. 130). Creary, et al. (2017) found that families’ sickle cell knowledge may decline over time. They state, “Knowledge achievement may be influenced by health literacy and baseline knowledge and may not be sustained over time” ( p. 698).

One recent study researched parental health literacy of children with cystic fibrosis (CF) (Kern, McColley, Watts, & Rychlik, 2015). This lone study compared the health literacy levels between Hispanic and non-Hispanic parents of children with CF. There was little statistical difference between the two groups of parents when data was corrected for socio-economic status. The authors suggest, “while parents of Hispanic CF children are at risk for low health literacy, this may not be a main cause of disparate outcomes in Hispanic CF patients” (Kern, McColley,

Watts, & Rychlik, 2015, p. 58). Incidentally, the authors noted that, as of 2015, they believed their study to be the first to look at the health literacy of parents whose child has CF.

Harrington (2015) explored health literacy in relation to parents of children with chronic kidney disease. The author stated that, “Over 100 articles were identified in the literature search. No articles were identified specific to caregiver and child health literacy as it relates to management of pediatric patients with CKD” (Harrington, 2015, p. 54). The author concluded by calling for more research, more evaluation tools, and more health literacy interventions.

### **Research Questions Or Hypotheses**

The health needs of CSHCN are varied and complex. Therefore, the health literacy needs of parents and caregivers of CSHCN are also varied and complex. The research in this area of study has been somewhat limited to date. It is vital that the specific needs of the parents and caregivers guide both the research and the implementation of health literacy programs. What communication methods do parents/caregivers find most helpful? What are the most effective ways to improve the health literacy of parents/caregivers of CSHCN? What are their perceived needs in terms of health education and health communication?

### **Research Methodology**

**Participant Population.** A qualitative survey was created and administered to assess the perception of health literacy needs of parents and caregivers of CSHCN in the Gainesville and Alachua County area. There were fifty-four participants, of whom fifty-one reported to be the parent or caregiver of a CSHCN, either full- or part-time. Participants were approached at either a special needs expo or online through Facebook special needs closed group. The survey was conducted electronically through Google Survey format. Respondents were asked about their perceptions on the quality of health communications with their child’s providers, their preferred

avenues of health communications, and their suggestions on how to improve their access to health information about their child's condition/s. It contained nine closed-ended questions and two open-ended questions. For the purpose of this survey, "health care provider" included doctors, nurses, physician assistants, or therapists.

**Limitations.** There were several limitations to the study. This was a time-limited study that occurred between January-March 2018. There was a small sample size of n=54. The 2017 census count for Alachua County was 266,944. The population under the age of 18 was 18.1%. Given the national statistic of around 15% of children and youth who have special health care needs, this would lead to an estimation of 7,200 children and youth in Alachua County with special health care needs.

The survey attempted to address language limitations. However, it was available only in written English. This was not a blind or randomized study. No personal or demographic data was recorded; a conscious attempt was made to keep questions to a minimum due to the time constraints at the conference where data was collected. The goal was to impede as little as possible on participants' activity at the expo. There was no data collected about where the child's providers were seen; it was felt that participants would be more open and honest if it were clear that the data would be strictly confidential and not be used for a specific provider (such as UF Health Shands). Finally, this study relied entirely on self-reported data.

**Findings.** A summary of the results is presented here; the full survey is available for reference in Appendix A. The survey addressed preferred methods of communication between caregivers and providers. The first question (Q1) asked if the respondent was the parent or caregiver of a CSHCN; 51 of 54 responded yes.

The second question (Q2) asked, “Which way(s) do you prefer to get information about your child’s health care needs?” Approximately eight out of ten parents/caregivers (81.5%) prefer to get health information about their child’s health in face-to-face conversations. The second favorite method (53.7%) was direct electronic communication with the health care providers, in the form of email or a patient portal system, such as MyChart. Somewhat surprisingly in this digital world, close to half of respondents selected printed materials (46.3%). An equal percent indicated Internet resources. Other choices were smart phone and iPad apps or classroom setting. Because respondents could choose more than one answer, the percentages do not equal 100%.

Two questions (Q3 & Q5) dealt with the source of health information for parents/caregivers. Question 3 asked, “Where do you get the MOST helpful information about your child’s need(s)?” The top two responses had an equal number of responses (n=14, 26.9%)—their providers and the Internet. Other choices were nurses (3.8%), other health care providers (15.4%), family or friends (17.3%), and other/write-in (n=4). The fifth question (Q5) was, “If you need help understanding your child’s health care needs, who do you ask first?” The respondents overwhelmingly chose the child’s doctors (n=36, 66.7%). The Internet or other health care providers (besides doctors and nurses) both garnered 11.1% of responses. Family and friends were the first choice for 7.4%, and nurses were first for 3.7% of respondents.

Three questions (Q4, Q6, Q9) addressed oral communications between providers and parents. When asked if the child’s providers use too much medical jargon or technical terms (Q4), 69.8% replied No, 26.4% replied Sometimes, and 3.8% replied Yes. In response to how much of provider information is understood, 48.1% stated that they “always understand what the health care providers say about my child’s health.” Half of respondents (n=27) answered, “I

understand most of what the health care providers say, but sometimes I don't." Finally, one person admitted, "I understand some of what the HC providers say, but most of the time I don't." When asked "If English is not your primary language, does your health care provider offer you materials or resources in your primary language?"(Q9), none of the respondents reported language as a barrier.

Two questions dealt with the level of shared decision-making and support parents felt they had in their child's health care, which are two components of family- and patient-centered care. When asked whether they felt like a partner in the child's health decision-making process, 59.3% always feel like a partner in making decisions on behalf of the child; 24.1% usually feel like a partner; 14.8% sometimes feel like a partner; and the remainder (1.9%) responded "not sure/don't know." Question 7 asked if they have someone, like a social worker or case worker, who helps them coordinate the child's health care needs. Of the fifty-three people who responded, 77.8% said No, 18.5% reported having a resource person to assist them, and 3.7% were not sure.

The final survey question (Q10) was open-ended: "What else would be helpful to you when learning about your child's health care needs?" There were 27 individual responses, which can be split into several broad categories: (a) better quality of provider communication, (b) more accessibility to providers, (c) interdisciplinary collaboration, (d) case management services, (e) more resources, and (f) support for mental health issues related to caring for a CSHCN.

Lastly, there was an opportunity to provide comments or suggestions. These four responses were as follows:

- "More speech therapist needed."

- “I don’t feel like my pediatrician has enough info on resources or she is not communicating them all.”
- “Thank you.”
- “Your survey seems very narrow.”

### **Discussion**

There is a lag between patient desire for good health information and actually obtaining that information. 81.5% of parents/caregivers prefer to get information about their child in face-to-face conversations. However, only 46% of respondents found these conversations most helpful. The majority of participants wanted health information to come straight from the child’s health care providers, with two-thirds (n=36, 66.7%) of respondents choosing this option. However, only 26.9% (n=14) of respondents reported their child’s providers as the “most helpful” source of health information. The parents want information from the providers, but the providers are not able to provide it in a way that is most useful.

Even though seven of ten parents (69.8%) responded “No” when asked if their child’s providers use too many medical or technical terms, less than half of respondents (48.1%) felt they always understood what their child’s providers say about the child’s health needs. One possible explanation for this disparity could be a reluctance to admit to a lack of understanding of medical terms; another explanation is that the quality of health communication goes far beyond spoken vocabulary.

Health literacy, particularly critical thinking skills, is needed to make decisions about a child’s health care. Shared decision-making has both impacts and is impacted by the health literacy levels of patients or their caregivers. This seems to be an area of strength with 83.4% of

parents/caregivers always or usually feeling like a partner in the decision-making process for their child's health.

All parents/caregivers of CSHCN, especially those with lower levels of health literacy, could benefit from a care coordinator. Most parents must research, coordinate, and make decisions about their child's health care needs with little guidance. Of the fifty-three people surveyed, 18.5% reported having a resource person, like a case worker or social worker, to help them coordinate their child's health care needs.

### **Conclusions and Future Study**

These findings suggest the need for further study of this subpopulation. While these parents/caregivers prefer one-on-one conversations to learn more about the CSHCN in their lives, few health insurance companies reimburse for the providers' time to support this. A concerted effort to provide coverage for patient health education would help provide the support these families need.

Additionally, for this group of participants, even when HC providers do not use medical jargon, health communication is still not optimal. Health care providers need to be trained properly in the most effective ways to educate patients and their families. Health communication, like all communication, is bi-directional. Both provider and patient (or parent) must both speak in a way that allows the other to listen, and listen in a way that allows the other to speak openly. This is perhaps the most difficult aspect of health literacy.

Health literacy can save lives as well as save money. According to the CDC (2016), "Limited health literacy costs the healthcare system money and results in higher than necessary morbidity and mortality" (Talking point #2). In *A Prescription to End Confusion*, the authors note that there are "...two types of costs associated with limited health literacy: economic costs

to society and the health-care system, and costs in terms of the human burden of disease”

(Nielsen-Bohlman, et al., 2004, p. 81). Health literate consumers help themselves, the health care system, and the nation. When the lives of special needs children are on the line, this becomes an even greater cause.

Because many children have more than one condition and many families have more than one child with special health care needs, it is vital that we learn how to address health literacy needs in this population. The World Health Organization (2013) described the need for patient and family empowerment; “Health literacy is rooted in the health promotion movement, with the aim to empower people as citizens, members of the workforce, consumers and patients so that they can better make decisions” (p. 22). This empowerment is essential for CSHCN and their families.



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## Appendix A

### Family-Centered Care and Families of Children with Special Health Care Needs (CSHCN) Survey

**Disclaimer.** “The purpose of this survey is to find ways to improve the partnership between families of Children with Special Health Care Needs (CSHCN) and health care providers. The goal is to help providers learn how to communicate effectively with families about their child’s health care needs. For the purpose of this survey, "health care provider" includes doctors, nurses, physician assistants, or therapists. Please answer each question to the best of your knowledge and ability. Your feedback is entirely voluntary and confidential. Please fill out this survey only once.”

Q1. Are you the parent or a caregiver (full-time or part-time) of a child with special health care needs?

- Yes
- No

Q2. Which way(s) do you prefer to get information about your child’s health care needs? Select all that apply.

- One-to-one conversations
- Classroom setting with other parents
- iPad or other device in the doctor’s office
- Smart phone app
- Print materials (brochures, books, etc.)

- Email, MyChart, etc.
- Internet (Search engines, social media, etc.)
- Other \_\_\_\_\_

Q3. Where do you get the MOST helpful information about your child's need(s)?

- Their doctors
- Their nurses
- Other health care providers
- Family or friends
- Internet (Search engines, social media, etc.)
- Other \_\_\_\_\_

Q4. Do you feel that your child's health care providers use too many medical or technical terms when talking to you?

- Yes
- No
- Sometimes

Q5. If you need help understanding information about your child's condition(s), who do you ask FIRST?

- Their doctors
- Their nurses
- Other health care providers

- Family or friends
- Internet

Q6. Which one of these statements BEST describes how you feel about the information you get from your child's health care providers?

- I always understand what the health care providers say about my child's health care.
- I understand most of what the health care providers say, but sometimes I don't.
- I understand some of what the health care providers say, but most of the time I don't.
- I rarely understand what my child's health care providers say about my child's health care.

Q7. Do you feel like a partner in your child's health care decision-making?

- Never
- Sometimes
- Usually
- Always
- Not sure / Don't know

Q8. Do you have someone (social worker, case worker, etc.) who helps you coordinate your child's health care needs?

- Yes
- No
- I'm not sure

Q9. If English is not your primary language, does your health care provider offer you materials or resources in your primary language?

- Yes
- No
- Sometimes
- English is my primary language

Q10. What else would be helpful to you when learning about your child's health care needs?

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Q11. Comments or Suggestions

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