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Health literacy and caregiver understanding in the CHD population

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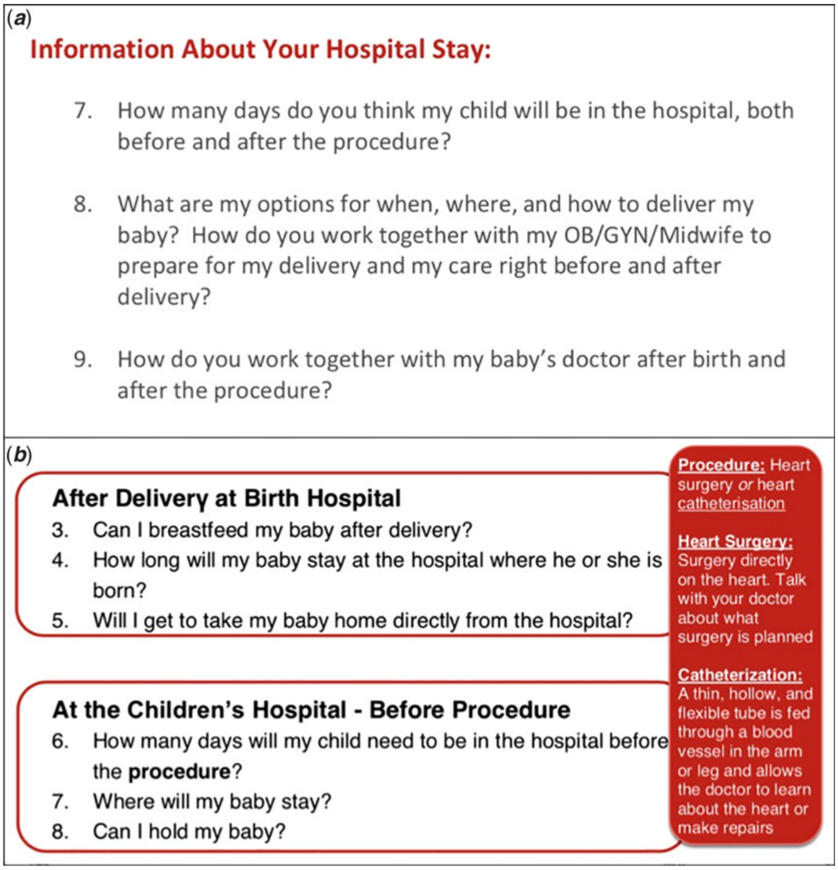
Abstract

Background: CHD is the most common birth defect type, with one-fourth of patients requiring intervention in the first year of life. Caregiver understanding of CHD may vary. Health literacy may be one factor contributing to this variability. *Methods:* The study occurred at a large, free-standing children's hospital. Recruitment occurred at a free-of-charge CHD camp and during outpatient cardiology follow-up visits. The study team revised the CHD Guided Questions Tool from an eighth- to a sixth-grade reading level. Caregivers of children with CHD completed the "Newest Vital Sign" health literacy screen and demographic surveys. Health literacy was categorised as "high" (Newest Vital Sign score 4–6) or "low" (score 0–3). Caregivers were randomised to read either the original or revised Guided Questions Tool and completed a validated survey measuring understandability and actionability of the Guided Questions Tool. Understandability and actionability data analysis used two-sample t-testing, and within demographic group differences in these parameters were assessed via one-way analysis of variance. *Results:* Eighty-two caregivers participated who were largely well educated with a high income. The majority (79.3%) of participants scored "high" for health literacy. No differences in understanding ($p = 0.43$) or actionability ($p = 0.11$) of the original and revised Guided Questions Tool were noted. There were no socio-economic-based differences in understandability or actionability ($p > 0.05$). There was a trend towards improved understanding of the revised tool ($p = 0.06$). *Conclusions:* This study demonstrated that readability of the Guided Questions Tool could be improved. Future work is needed to expand the study population and further understand health literacy's impact on the CHD community.

CHD, the most common congenital defect, affects nearly 40,000 newborns each year in the United States of America.[1] Approximately, 25% of these children will require an intervention during the first year of life; hence, caregivers are frequently faced with trying to understand not only the disease process itself but also the prognosis, necessary procedures, and associated outcomes, as well as the common morbidities.[1] Although the overall CHD population is diverse, impacting all racial, ethnic, and socio-economic groups,[2] disparities exist as related to morbidity and mortality.[3,4] Clinicians must recognise the challenges faced by caregivers processing new and complex information while caring for a child with complex medical needs, all the while remaining cognisant of the implications within vulnerable populations.

The US Department of Health and Human Services called for improving patient and family education in its *Healthy People 2020* campaign: specifically, to "increase the proportion of persons who report their health provider always gave them easy-to-understand instructions about what to do to take care of their illness of health condition."[5] This call is imperative given that approximately 90 million American adults have literacy skills at less than a high school level,[6] and evidence suggests that most health information is currently written at a high school reading level or higher.[7–11] Specifically, health literacy is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[6,12,13] An individual's health literacy is contingent not only on education but also on socio-economic status, culture, language, and the health-setting in which the information itself is delivered.[6] As a result, there is growing recognition within the CHD community that health literacy improvement is necessary.[14]

The Conquering CHD Guided Questions Tool[15] (https://www.conqueringchd.org/guided-questions-tool/) is a CHD-specific, standardised caregiver education tool that was created in 2015 with the aim of assisting families with their paediatric cardiology consultations. This tool was co-created by multiple content stakeholders, including caregivers, advocacy experts, and clinicians. However, in its current form, the Guided Questions Tool may not meet the aims of understanding called for by the Healthy People 2020 campaign.[5] In particular, the reading



(a)

Information About Your Hospital Stay:

7. How many days do you think my child will be in the hospital, both before and after the procedure?
8. What are my options for when, where, and how to deliver my baby? How do you work together with my OB/GYN/Midwife to prepare for my delivery and my care right before and after delivery?
9. How do you work together with my baby's doctor after birth and after the procedure?

(b)

After Delivery at Birth Hospital

3. Can I breastfeed my baby after delivery?
4. How long will my baby stay at the hospital where he or she is born?
5. Will I get to take my baby home directly from the hospital?

At the Children's Hospital - Before Procedure

6. How many days will my child need to be in the hospital before the **procedure**?
7. Where will my baby stay?
8. Can I hold my baby?

Procedure: Heart surgery *or* heart catheterisation

Heart Surgery: Surgery directly on the heart. Talk with your doctor about what surgery is planned

Catheterization: A thin, hollow, and flexible tube is fed through a blood vessel in the arm or leg and allows the doctor to learn about the heart or make repairs

Figure 1. (***a***) Original Guided Questions Tool in truncated format for study administration.[15] (***b***) Revised Guided Questions Tool, showing reorganisation of questions into "Phase of Care," division of questions itemised into individual bullet points, shortened overall length, removal of jargon, bolded terms when necessary, and co-location of defined terms.

level is measured at an eighth-grade reading level based on the Fry Readability Scale[16] despite recommendations that healthcare information be written at a sixth-grade level or below.[6,17] Thus, this study team revised the original Guided Questions Tool to improve readability and overall efficacy from a health literacy perspective.

The primary aim of the study team was to measure caregiver health literacy scores within the CHD community and evaluate the association of those scores with understanding of the Guided Questions Tool. We hypothesised that low health literacy scores would be associated with decreased understanding of the Guided Questions Tool. We also aimed to determine the association of demographic factors, such as caregiver age and socio-economic status with understanding of the Guided Questions Tool. The secondary aim was to evaluate the understandability and actionability of a revised Guided Questions Tool, written at the sixth-grade level, relative to the original Guided Questions Tool.

Materials and methods

Guided Questions Tool revision

The original Guided Questions Tool was revised by the study author team with attention to the tenants of health literacy using guidance from "toolkits" published by the Agency for Healthcare Research and Quality[18] and the Centers for Medicaid and Medicare Services.[19] Specifically, the original Guided Questions Tool is composed of 17 labelled "questions" formatted as distinct paragraphs with additional questions embedded in each paragraph (Fig 1a). Consistent with Agency for Healthcare Research and Quality and Centers for Medicaid and Medicare Services recommendations, the revised Guided Questions Tool separated all questions, a total of 37, into a "bulleted" format such that they could each be easily identified individually. These questions were then reorganised into categories defined by "Phase of Care," included medical jargon was minimised and question length was further truncated with the ultimate aim of creating questions no longer than one line in length (Fig 1b). Where medical jargon was necessary, such as use of the terms "procedure" or "catheterization," the text was bolded and underlined. These terms were then defined in the margins of the document immediately adjacent to the text. The resulting revised Guided Questions Tool measured at a sixth-grade reading level based again on the Fry Readability Scale.[16]

Study population

Phase I of this study took place at the Cincinnati Children's Hospital Heart Institute Family Camp. Every year, since 2003, Family Camp invites families of children aged 0–21 years affected by CHD or acquired heart disease to Camp Joy in Clarksville, OH[20] for 3 days (Friday–Sunday) every May. While participants are largely cared for by Cincinnati Children's Hospital, Family Camp is open to patients and families from all hospital systems and free of charge to attend. Families do, however, need to provide their own transportation and have the means to be free from other responsibilities, such as employment, for a weekend.

Families were introduced to the study during the Saturday morning education session and all were invited to participate. All caregivers within a family could participate separately as long as they were over the age of 18 years, and the child in their care was aged 0–18 years at the time of study enrolment. Caregivers with limited English proficiency were excluded from participating in the study. In total, 123 camp participants were eligible and approached for inclusion.

Phase II of participant enrollment took place in the paediatric cardiology ambulatory clinic at Cincinnati Children's Hospital over the course of 4-week period (29 August 2019 to 27 September 2019). Recruitment was limited to those participants present for a follow-up clinic visit and fulfilling the same criteria as Phase I. Recruitment would occur at the beginning of the clinic visit and participation could occur at any time during the course of the visit as time allowed. In total, 58 parent participants were approached for inclusion in the clinic setting.

Documentation of informed consent was obtained from all participants. This study was approved as an exempt study by the Institutional Review Board at Cincinnati Children's Hospital.

Survey administration

The health literacy of all participants was assessed via a validated screening tool called the "Newest Vital Sign."[12] The Newest Vital Sign requires participants to answer six questions regarding a nutrition label from a container of ice cream. These questions were read aloud by a study team member to participants. Participants were able to view the ice cream label for reference while answering the questions which were recorded by a study team member. There were 3 minutes allotted for this portion of the study. Participants were then asked to complete information related to demographics and their child's cardiac diagnosis.

Participants were then randomised using a random number sequence generator to independently read either the original Guided Questions Tool or the revised Guided Questions Tool. Prior to study administration, the original Guided Questions Tool and the revised Guided Questions Tool were shortened such that participants received matched length formats. Given that original Guided Questions Tool revision required division of paragraphs and shortening of questions, the formats were not matched based on number of questions rather on number of pages such that each participant had a matched length of content to read. The shortened versions were created to allow for timely study administration. Each version maintained its full-length readability grade level by Fry Readability Scale. After reading the respective version of the Guided Questions Tool, participants were asked to complete an adapted "Patient Education Materials Assessment Tool for Printable Materials".[21] The Patient Education Materials Assessment Tool for Printable Materials is a validated screening tool produced by the Agency for Healthcare Research and Quality to measure understanding and actionability of printed material. Per the Agency for Healthcare Research and Quality, a material is defined as understandable "when consumers of diverse backgrounds and varying levels of health literacy can process and explain key messages" and actionable when the same consumers "can identify what they can do based on the information presented."[22] Adaptation of the Patient Education Materials Assessment Tool for Printable Materials included removing questions that were not applicable to the Guided Questions Tool, such as questions about numbers, graphs, and calculations. This resulted in removal of a total of five questions from the original Patient Education Materials Assessment Tool for Printable Materials. At conclusion of the Patient Education Materials Assessment Tool for Printable Materials, participants were given a space to provide qualitative commentary regarding their study version of the Guided Questions Tool.

Data analysis

All demographic data were gathered and examined for completeness and evidence of missing data. Demographic data included gender, caregiver relationship to patient (parent, legal guardian, and extended family), age, race, primary language, highest degree achieved, household income prior to tax, age of patient (current, at diagnosis, and at first procedure), and type of cardiac condition (congenital/structural, electrophysiologic, and acquired). The range of scores on the Newest Vital Sign screen was collected and examined for data validity and completeness. Newest Vital Sign scores were divided into low (3 or less correct) and high (4–6 correct) performance according to the tool's validated scoring system.[12]

Two-sample t-testing was employed to compare understandability and actionability scores between original Guided Questions Tool and revised Guided Questions Tool in both the low and high health literacy groups. When the health literacy score was examined as a continuous variable, a Pearson's correlation was used to determine if there was any relationship between health literacy and understandability. One-way analysis of variance was used to elucidate if differences in understandability of the Guided Questions Tool existed within the following categories: education level, household income, and caregiver age.

Results

A total of 82 CHD caregivers were enrolled in the study (51 and 31 in Phase I and II, respectively). When examining the population as divided by those randomised to receive the original Guided Questions Tool versus revised Guided Questions Tool, there were no significant demographic differences between the groups ($p > 0.05$). The population was well educated, with a large portion of the population reporting a college education or more ("College" and "Graduate School" combined, $n = 59$, 72%). Regarding income, 72% of the population reported at least $50,000 of pre-tax income per year, with 37% ($n = 30$) reporting over $100,000 of pre-tax income per year (Table 1). When compared to income and education statistics of the sampled population, the study group had skewed characteristics as shown in Table 2.

The majority of the population scored in the top tier for health literacy ($n = 65$, 79.3%; Table 3). In addition, socio-economic status data for the various health literacy tiers demonstrate overall high education and income levels distributed across all health literacy categories. There was not a correlation between health literacy score and understandability score ($r = 0.06$). Furthermore, in regard to caregiver age, there was no difference in understandability ($p = 0.83$) or actionability ($p = 0.67$) by age group. In addition, there was also not a difference in understandability ($p > 0.99$) or actionability ($p = 0.99$) in groups based on pre-tax household income.

When examining understandability scores according to original Guided Questions Tool compared to revised Guided Questions Tool, there was a strong trend towards improved understandability with the revised Guided Questions Tool ($p = 0.06$). There was no significant difference in actionability between the two versions of the Guided Questions Tool ($p = 0.46$). When exploring the qualitative data, some common themes emerged. In regard to the original Guided Questions Tool, there were consistent requests

Table 1. Demographic data.

	Total (n = 82)	Original GQT (n = 41)	Revised GQT (n = 41)	p-Value
Gender				0.165
Male	25	16	9	
Female	56	25	31	
Chose not to disclose	1	0	1	
Caregiver relationship				0.709
Parent	76	39	37	
Guardian	2	1	1	
Extended family	3	1	2	
Chose not to disclose	1	0	1	
Caregiver age (years)				0.872
20–25	3	2	1	
25–30	8	6	2	
30–35	15	7	8	
35–40	24	13	11	
40–50	21	9	12	
50–60	7	3	4	
>60	2	1	1	
Chose not to disclose	2	0	2	
Caregiver race				0.067
Asian	2	2	0	
Black or African American	6	3	3	
White	71	34	37	
Other	2	2	0	
Chose not to disclose	1	0	1	
Caregiver primary language				0.390
English	79	39	40	
Spanish	1	1	0	
Other	1	1	0	
Chose not to disclose	1	0	1	
Caregiver highest degree				0.461
Less than high school	1	1	0	
High school/GED	21	13	8	
College	37	17	20	
Graduate school	22	10	12	
Chose not to disclose	1	0	1	
Household income				0.298
<$25,000	9	6	3	
$25,000–$49,000	12	8	4	
$50,000–$99,000	29	14	15	
>$100,000	30	13	17	
Chose not to disclose	2	0	2	
Condition type				0.721
Congenital/structural	76	38	38	
Electrophysiological	3	2	1	
Acquired/cardiomyopathy	2	1	1	
Chose not to disclose	1	1	0	

GED = General educational development; GQT = Guided Questions Tool.

Table 2. Population-level demographic data representative of general population sampled.[32]

	Median income (pre-tax, based on 2018 data, $)	Percentage of population with bachelor's degree or higher, if ≥ 25 years old
Ohio	54,533	27.8
Cincinnati	38,542	36.1
Kentucky	48,392	23.6
Indiana	54,325	25.9

Table 3 "Newest Vital Sign"[12] scores.

"Newest Vital Sign"[12] score (resulting HL category)	No. of participants (%)	No. of participants in HL category with ≥ high school education (%)	No. of participants in HL category with ≥ $50,000 annual pre-tax income (%)
0–1 (High likelihood of limited literacy)	4 (4.8)	3 (75)	2 (50)
2–3 (Possibility of limited literacy)	13 (15.9)	5 (38.5)	8 (61.5)
4–6 (Almost always indicates adequate literacy)	65 (79.3)	26 (40)	49 (75.4)

HL = health literacy.
HL scores and some associated socio-economic-related demographics demonstrating overall highly educated and affluent population distributed amongst all HL groups.

for improved visual aids, space to write comments, notes, or questions, and a bulleted or checklist format. The qualitative comments based on the revised Guided Questions Tool also requested more visual aids and a desire for space to take notes but did not request an abridged or modified format.

Discussion

Using tenants of health literacy as suggested by the Agency for Healthcare Research and Quality[18] and the Centers for Medicaid and Medicare Services,[19] the Guided Questions Tool was successfully revised from an eighth-grade reading level to a sixth-grade level as determined by the Fry Readability Scale.[16] Based on the working definition of health literacy used by the National Academy of Medicine,[6] our revisions were associated with improved processing and understandability of information. While the difference in understandability between the original Guided Questions Tool and the revised Guided Questions Tool only approached statistical significance, it may well be that further difference would be measured across a more heterogenous population.

There is a paucity of information regarding health literacy in paediatric cardiology and health outcomes. Thus, we are encouraged by the trend in our results and motivated by the fact that this was the first study of its kind to specifically address health literacy of print media educational tools in paediatric cardiology. This work is important not only with regard to baseline physician stewardship for effective communication and education but also when considering future health outcomes for CHD patients given their chronic healthcare needs. Enhancing health literacy has been associated with improved metrics in several areas of healthcare. In the context of chronic paediatric illness, improving health literacy in paediatric asthma care has been shown to be associated with decreased emergency room visits and hospitalisations, as well as improvement in self-efficacy.[23,24] In addition, refining the educational process, and therefore health literacy, involved in dosing medications in paediatrics has been shown to circumvent adverse health outcomes related to improper dosing.[25] This is particularly important given that low parent literacy has been independently shown to be a predictor of difficulty understanding over-the-counter medications.[26] Finally, a relationship between low health literacy and all-cause mortality has been demonstrated in adult populations.[27] Therefore, we are hopeful that this investment in the health literacy of materials designed for our CHD population may also have outcome-related impacts as the patients in question progress in their CHD journey.

Although our study did not identify any specific demographic factors as independent predictors of poor understanding of either version of the Guided Questions Tool, prior population-based studies have demonstrated differential health literacy based on demographic factors. Low education level, low income, Black/Hispanic ethnicity, and birth outside of the United States of America have all been associated with low health literacy.[26] The National Assessment of Adult Literacy has also demonstrated that adults living below the poverty level have lower than average literacy.[28] As a result, attention to the health literacy of educational tools should occur with these vulnerable populations in mind.

Health inequities based on race, ethnicity, and socio-economic status within the CHD population independent of established literacy risks have also been established previously. Several additional factors likely contribute to health disparities including structural (i.e., social class-based) inequities, such as access to care, as well as implicit bias.[29] Differential mortality based on race and ethnicity has been demonstrated in various CHDs, with notably increased mortality in the postnatal and early childhood period for non-Hispanic Blacks and Hispanic White infants.[3,4] Similarly, increases in post-operative mortality have been noted in non-White patients[30,31] and those with Medicaid insurance, while these patients also had increased odds of non-elective admissions for congenital heart surgery.[30] Perhaps most significant to the aims of this study, Black patients and those with Medicaid insurance were also shown to have higher odds of referral to high-mortality hospitals,[30] highlighting the importance that all caregivers understand their child's diagnosis, associated treatments, and options for care. Limited health literacy in specific patient demographics compounded with poorer outcomes associated with vulnerable populations, as well as the frequent need for rapid decision-making under stress, highlights the critical importance of improved health literacy in CHD.[14]

The results of this study are impacted by the following limitations. The range of health literacy scores measured during this study skewed towards highly health literate caregivers. Despite efforts to measure families outside of the hospital setting, as well as in general paediatric cardiology clinic, we were not able to capture a sample that was entirely generalisable. This limitation is highlighted by the fact that 79% of the study sample demonstrated proficient health literacy compared to the expected value of 12% in the general population.[28] Therefore, despite an overall sufficient sample size to demonstrate difference in understanding and actionability, we were likely under-powered in participants with low health literacy. Additional limitations include the fact that the study took place at a single centre and included a population from a particular geographic area. Overall, participants represented a narrower range of demographic background than the study was designed to capture.

In summary, using strategies specifically aimed to improve the health literacy of print material, our study team successfully revised a standardised educational tool currently utilised in multiple paediatric cardiac care settings. These revisions resulted in a trend towards improved caregiver understandability. The findings of this study highlight the importance, and feasibility, of addressing health literacy when creating CHD education materials. Next steps include testing of the revised Guided Questions Tool in a more generalisable population sample.

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Conflicts of interest. None.

Ethical Standards. Not applicable.

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