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Health literacy in CHD

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Editorial

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Health literacy is essential for patients and caregivers to be actively involved in the development and execution of their care plan. Health literacy is more than an individual's capacity to read, encompassing the ability to read, interpret, understand, and retain health information.[1] This has a tremendous impact on patient education, satisfaction, adherence, follow-up, and ultimately outcomes. Yet, the United States Department of Education and the National Center for Education Statistics highlighted that 35% of the adult population have low health literacy, while only 15% have attained the highest health literacy skills, confirming that many individuals face some health literacy challenges.[2,3]

Low health literacy has negative implications for economic impact in addition to short- and long-term outcomes. Individuals with low health literacy spend on average $500 more on office visits, $50 more on ED visits, and $2600 more on prescriptions than those who do not have health literacy challenges with an estimated annual cost to the U.S. economy totally $106 billion to $238 billion.[4] For health systems, low health literacy manifests as increased costs, with increased rates of hospitalisation and worse outcomes.[5] For these reasons, the American Academy of Pediatrics, Centers for Disease Control, and Joint Commission have all identified health literacy as a critical component of quality care and safety.[6,7,8]

Limited health literacy in adults is linked to a higher incidence of serious medication errors, higher rates of emergency room visits, hospitalisations, poorer preventative care for children they are caring for, and increased mortality.[5] In a retrospective review of reported safety events, a large Children's Hospital found that several safety events contained an element of health literacy as a contributing cause and concluded that "Health literacy-related safety events occur in the healthcare environment and impact all types of safety event outcomes".[9]

Challenges in health literacy

Barriers that can influence health literacy include social determinants of health in addition to circumstantial conditions such as stress, learning new or complex information, and distracting learning environments.[4] Examples of social determinants include education, income, food security, English proficiency, age, and disability.[6] When examining specific social determinants of health, parents with lower socio-economic status and lower education are likely to have lower health literacy.[10] These issues are closely associated with outcomes, as poor understanding of a child's CHD likely results in higher rates of unintended hospital admission and resource requirement and lower health-related quality of life.[10] Failure to address ownership of care and literacy can result in lapses in care, morbidity, mortality, and poor treatment adherence.[11] Health literacy is often overestimated by providers despite the existence of tools to identify at-risk patients and families.[12] In addition, families with lower health literacy are also more likely to reside in resource-poor, rural areas and may be further affected by limited access to care at tertiary centres.[10]

Health literacy is a challenge for families of medically complex children and those for whom English is not their first language.[13] One study evaluating Emergency Department care found that 74% of Spanish-speaking patients had less-than-adequate health literacy.[14] For this reason, it is imperative to assess the preferred language of patients and families. Further, it is critical to utilize professional interpreter services and provide materials in a patient's language of comfort, including educational materials and prescriptions, to assure understanding and support care outside hospitals and clinics.

Thus, opportunities to address health literacy are also moments to address health equity and social justice. All providers must understand the core principles of health literacy to serve patients and families completely and ultimately optimise health outcomes.

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Health literacy challenges in congenital heart disease

Fetal diagnosis

In the context of CHD, affected patients and families experience unique circumstances and care that require an understanding of health literacy. This process begins for some families with fetal diagnoses. This process of learning foreign and complicated subject matter under significant duress represents immense challenges in assuring adequate information delivery and understanding in the limited opportunities associated with fetal echocardiography and counseling. Coordination with colleagues in obstetrics and maternal–fetal medicine to have repeated teaching sessions in each visit and over time is imperative to assure adequate knowledge of the CHD affecting the fetus and treatment options before and after delivery. Post-natal diagnoses compound things further requiring the same amount of knowledge intake in a significantly shorter amount of time.

Additional research aims to assess the qualitative themes associated with receiving information regarding prenatal diagnosis.[15] Identified themes include understanding information while looking to the future, relationships with trustworthy, honest providers, and information overload when accessing internet resources.[15]

Inpatient and discharge care

Health literacy presents unique challenges in the inpatient setting. The experience of hospitalization is an inherently stressful time, and regardless of capacity to understand and retain healthcare information, many families struggle with learning and retention during this period. The Health Literacy Task Force at a Children's Hospital documented some of the challenges their caregivers had faced via video. One mother recounted how she did not understand forms that she was being asked to sign due to managing her fussy baby, while the information was being explained. Another mother discussed her misunderstanding of her daughter's diagnosis. Yet another told of how she could barely remember anything that a physician said to her due to the stress of discovering her daughter's diagnosis.[16]

Discharge care is critical, but findings suggest that families often feel "rushed" in this education.[17] Specifically, families report discomfort with chest tube site care and think that a mobile application may assist their learning and access to information.[17] Further evidence supports the inadequacy of the typical day of discharge teaching. Interestingly, this is true for both families and providers. Of parents, 85% felt prepared for discharge, 58% reported most of the learning on the day of discharge, and 31% said their questions were not completely answered.[18] Early in hospitalisation, setting clear expectations for recovery and preparing families for the challenging immediate postoperative days is critical to assure readiness for learning ahead of discharge. These early encounters offer opportunities for tailored, problem-based education alongside a broader dialogue regarding the patient's CHD while benefiting from the ongoing support of the in-patient care team. It is paramount to consider these encounters in the more comprehensive continuum of patient education and health literacy across the lifespan of CHD.

Access to valid internet sources

Further, challenges exist in accessing reliable, accurate health information on the internet.[20] An evaluation of sources for parents receiving a prenatal diagnosis of CHD determined the poor quality of information regarding the effect of not intervening, shared decision-making models, goals of treatment, and quality of life.[20] Further, most information was not current, poorly produced, and lacked reader engagement.[20] It is also essential to consider the limitations of infrastructure and socio-economic determinants in determining patient and family access to health information. Thorough searching requires a computer or smartphone and reliable internet service, not available in many rural or disadvantaged communities across the USA. However, when available, providers may assist in vetting information, connecting patients and families to reputable advocacy organizations, and directing to reliable and reputable sources.

Adolescent, young adult, and transition care

Health literacy challenges in CHD are not limited to children and parents. Very few adults with CHD can recall their specific diagnosis.[21] In an evaluation of knowledge among adolescent patients and their parents, caretakers consistently demonstrated higher CHD knowledge than their children but struggled with locating a heart defect on a CHD diagram and risk factors for subacute bacterial endocarditis.[22] Among the adolescents, parental knowledge was a predictor of improved understanding of their CHD.[22] However, both groups reflected levels of performance that were less than ideal.[22] For this reason, interventions must address the needs of both adolescent patients and parents as providers introduce concepts and independence ahead of the transition to adult care.[22] These conversations foster not only ownership of care but also independence and understanding. Adolescents and young adults are among the most vulnerable to gaps in care, and initiation of education in this manner, directed towards both parents and children, must begin as soon as patients demonstrate readiness to learn about their CHD.

Studies show that between 61 and 83% of young adults have no follow-up or have a gap in care after being discharged from a paediatric institution. Patients with gaps in care are more likely to need urgent interventions, have higher rates of hospitalisation and more frequent ED visits, and experience untreated complications related to their cardiac diagnosis. A typical patient misconception that exhibits a lack of understanding about CHD is that a patient's condition was cured rather than palliated. This has important implications for choices that range from lifestyle, career, and family planning.[23]

Improving health literacy in CHD

Simple educational approaches, including teaching back, have proven successful in improving health literacy.[11] Additional strategies include using simple language, confirmation of understanding, and vetting of written materials to assure understanding for all patients.[13] Systematic models of patient education have also revealed effectiveness in patient activation, engagement and understanding, including an organized approach with individual learning plans, conversant education, and motivational interviewing.[24] This has also improved the transition from paediatric to adult congenital heart care alongside the introduction of tools to assess literacy and resilience.[24] As new educational tools are developed to improve patient understanding, it is crucial to continue to assess their effectiveness, accuracy, and accessibility to improve sustainability and impact of interventions.

It is essential to understand that health care providers cannot identify a patient or family with low health literacy by outward appearance. Additionally, as previously discussed, health literacy

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is not a "fixed" trait and can be affected by variables such as distracted environments, lack of sleep, and stress. Considering this information, providers should use a standard approach with all patients and families regardless of what their health literacy is assumed to be. A literature review was conducted, and the following specific interventions have been validated as tangible ways to communicate with patients universally:

- Simplifying and Organizing Information – Information should be organised logically, and the content should be simplified as much as possible. This will reduce cognitive load, the amount of mental demand the information presents. Adults who are given shorter amounts of information have better comprehension. Complex instructions have been linked to lower knowledge of diagnosis, medication information, and follow-up instructions, including not attending appointments and failing to pick up prescriptions.
- Clear and Action-Oriented Instructions – Examples include giving medication instructions in the context of standard periods like the morning, noon, evening, and night instead of instructions like two times per day. Please stay away from excessive background information, as it may be distracting.
- Chunking – This strategy involves chunking information into smaller, manageable pieces.
- Plain Language – Lay terms should be used, and medical jargon should be avoided. Sentences should be short and straightforward.
- Demonstration – Using verbal and visual channels is thought to result in more accessible and quicker learning. For example, demonstrating how to draw up and administer liquid medications can improve accuracy.
- Teach Back – Teach back is a top safety practice according to the AHRQ. To create a shame-free environment, but the responsibility of learning on the clinician. Studies have shown that teaching back can lead to improved recall.
- Pictographic and Video Instructions – If these are used, they should use the same language that has been provided via written information.[4]

Health literate strategies cannot be solely implemented at an individual provider level. Systems should accommodate the unpredictability of limited health literacy skills and integrate health literacy into planning, evaluation, and patient safety measures. They should prepare the entire workforce and monitor progress. "Being a health literate organization is more than initiating a few projects that address health literacy; it means that health literacy is an organizational value. Health literacy strategies are infused throughout the organization and embraced as part of the organization's core business".[5]

Recent interventions have aimed at utilising technology, including mobile phone applications. An evaluation of one such intervention, the Adult Congenital Heart Association and American College of Cardiology's Health Passport, demonstrates that most patients have access to suitable devices, and a majority of patients are willing to utilise their devices to store and access health information associated with their CHD.[21] Again, this technological solution is limited by access to devices, wireless data, and reliable internet resources. However, implementing such a tool offers a unique method to assist in the transition of care and improve patient and family familiarity with their CHD.

Patient advocacy organizations, including Conquering CHD, have developed tools to assist patients and families in CHD-related knowledge acquisition. The Guided Questions series and blog available from Conquering CHD are among these tools. The "Guided Questions tool has undergone revision, including rewriting the material to a sixth-grade reading level.[25] Though the sample was interpreted as equally helpful relative to the original iteration at an eighth-grade level, re-evaluation with a more diverse sample may prove that simplifying this information and vocabulary makes the tool more accessible to more families.[25] This includes providing services and materials in a patient's preferred language. Resources from Conquering CHD are now available in Spanish to improve patient access to these resources and to assure that all families affected by CHD can access these materials in a language that they can understand, recall, and apply.

Strategies to address health literacy must be implemented across the lifespan. Structuring visits in adolescence towards transition, patient activation, and educational assessment have proven effective in improving literacy in the transition from paediatric to adult congenital care.[11] This furthers the importance of initiating conversations regarding the transition to adult congenital care beginning before adolescence. This affirms the principle of lifelong CHD care and learning. Even among adults, each visit should include education specific to patient needs, including diagnosis, history of intervention, monitoring schedule, expected course, medications, and their side effects.

Conclusions

Addressing health literacy is the responsibility of all healthcare providers, as is the physician's role as an educator of tremendous importance in assuring patient understanding and adherence. Generally, patients who receive structured education about CHD demonstrate greater knowledge than those without such an intervention, independent of determinants of patient knowledge and learning.[26] However, despite the simplicity of this finding, there are numerous gaps in addressing opportunities for health literacy.[26] Each inpatient or outpatient encounter beginning in the fetal period must be regarded not only as a clinical evaluation but also as a teaching session. It is only through repetition, determination of readiness to receive information, identification of learning preferences, and an individualised approach that providers may work to improve health equity in each encounter, and ultimately for the benefit of patients affected by CHD.

Further patient-engaged research is required to characterise the health literacy needs of patients and families affected by CHD. Among these are improved understanding of comorbidities and the social determinants of health, improved assessment of paediatric patient literacy, understanding of caregiver literacy, and the impact of literacy on healthcare quality and cost.[27]

Building rapport with patients and families extends this healing and educational mission, as earning the trust and comfort of those served allows for transparency, comfort in discussing challenging topics, and an attentive ear in each visit. Aside from screening for biological factors and social determinants of health, providers must also approach health literacy as a factor that can modulate a patient's experience with CHD and, ultimately, their outcomes.

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