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Pediatric Caregiver Health Literacy: Comparing Perceptions of Pediatricians and Nurse Practitioners

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PEDIATRIC CAREGIVER HEALTH LITERACY: COMPARING PERCEPTIONS OF PEDIATRICIANS AND NURSE PRACTITIONERS

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By

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ABSTRACT

Throughout life, most people will interact with the healthcare system to manage information in order to make healthcare decisions. Health literacy is the ability to comprehend health information needed to make healthcare decisions. Pediatric patients often do not have a voice in their healthcare decisions; therefore, their health outcomes may be affected by the health literacy of their caregivers. In addition, the child's health may be impacted by the ability of the healthcare team to provide appropriate health education. The purpose of this honors thesis was to determine pediatric healthcare providers' perception of health literacy in their practices. Qualitative data was collected through semi-structured interviews with two nurse practitioners and one pediatrician. Results of the interviews indicated that providers obtain information through history taking and determine caregiver health literacy based on their ability to follow verbal and written instructions. Although lack of time is a barrier, healthcare providers can increase health literacy in their practices by providing feedback to caregivers in a caring, nonjudgmental manner.

Keywords: *pediatric patients, caregiver health literacy, primary care, provider perception, nurse practitioner, pediatrician*

I dedicate this thesis to my husband, Ryan, who has been by my side, pointing me to the Lord throughout this process and forevermore. I also dedicate my findings to my future pediatric patients and their caregivers. I strive to be a healthcare provider that goes above and beyond to ensure their needs are met so they feel comfortable managing their health. This research process has allowed me to feel more confident in achieving that goal in my practice.

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INTRODUCTION

Consider a situation in which you are the parent of an ill child. For the past few days, your child, who is only 18 months old, has been experiencing a runny nose and a cough that has been worsening. Therefore, you take her to the pediatrician's office. The pediatric provider examines your child and says, "Your child most likely has bronchiolitis caused by respiratory syncytial virus. We are going to confirm with a nasopharyngeal wash. I encourage oral rehydration paired with over the counter medications, and if it gets worse to the point of wheezing, go to your nearest emergency room. Call the office if you have any questions. Thank you!" The pediatric provider leaves, and you are left full of fear, unsure of what those instructions meant. Regardless of education level, fear or confusion after any doctor's visit is not uncommon in the United States. Often, these feelings are caused by the inability to process and manage the information presented at the visit.

Health literacy is defined by the Patient Protection and Affordable Care Act of 2010, Title V, as "the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions" (Centers for Disease Control and Prevention (CDC), 2020, para. 2). At times, caregivers must utilize their health literacy level to make health decisions for children who cannot make decisions for themselves. Health literacy is further broken down into personal health literacy and organizational health literacy in Healthy People 2030. Personal health literacy involves the extent to which individuals

can engage with their health information, while organizational health literacy involves how well an organization can equitably empower individuals to utilize resources to make informed healthcare decisions for themselves and others (U.S. Department of Health and Human Services (HHS), 2020). This newly-revised definition of health literacy implies that health literacy can be improved collaboratively and is the responsibility of the patient as well as the healthcare provider.

In 2003, the National Assessment of Adult Literacy (NAAL) was conducted; this assessment evaluated adult literacy in the United States through the use of various tasks completed by adults as opposed to subjective assessments. This type of large-scale study was the first of its kind to be completed since 1992 (Kutner et al., 2006). The study, summarized by Cutilli and Bennett (2009) in order to be more easily accessible to healthcare workers, found that 36% of the adult participants had basic or below basic health literacy skills. This statistic indicates that approximately one third of adults in the United States may have inadequate health literacy.

Although the last NAAL study was conducted in 2003, there are implications for healthcare today. If patients cannot understand their healthcare information, they cannot effectively manage their own care. While an individual can control his or her literacy to a certain extent, there are always nonmodifiable factors that affect an individual's health literacy such as racial/ethnic group or age (Healthy People, 2020). Results from the NAAL, as cited by Healthy People (2020), indicate that on average Hispanic adults have the lowest health literacy. African American adults have the second lowest health literacy levels overall, followed by American Indian/Alaskan Native adults (Healthy People,

2020). Adults of any racial or ethnic group over the age of 65 are also at higher risk for inadequate health literacy levels (Healthy People, 2020).

Due to these nonmodifiable factors, organizational health literacy plays a vital role in empowering vulnerable populations to properly manage their health. Healthcare providers are responsible for serving their patient population by equitably meeting their health literacy needs (HHS, 2020). Patients may leave their provider's office or be discharged from the hospital with a great deal of confusion and several questions, while the healthcare provider may not be aware that the patient does not understand the instructions provided. Pediatric caregivers bear the responsibility of their own health information as well as their child's. Because pediatric patients have very little responsibility for their health decisions, they must bear the consequences if their caregivers demonstrate low health literacy. A caregiver is any person who provides direct care to a child, elderly person, or a chronically ill person (Merriam-Webster, n.d.). Caregivers in the pediatric primary care setting may include but are not limited to, parents, relatives, foster parents, and social workers.

While there is a great deal of literature available regarding the health literacy levels of adults, there is a lesser amount of literature available that focuses on the implications of low caregiver health literacy for pediatric patients. Most research has been conducted on the impact of caregiver health literacy on pediatric patient outcomes in specialized settings such as the neonatal intensive care unit (NICU), diabetes clinics, or nephrology wards. However, no literature was found regarding a pediatric primary care setting—where most caregivers may find themselves with their child each year. In 2018, 93.6% of children saw a healthcare professional (CDC, 2019). This statistic further

emphasizes the value of proper health teaching and health literacy management at the primary care level.

During the time that research for this honors thesis was planned and conducted, the implications of caregiver health literacy on pediatric health outcomes could not be directly observed in the pediatric primary care setting due to the COVID-19 pandemic. Therefore, the researcher opted to focus on the organizational health literacy perspective of the effect of caregiver health literacy on pediatric patient outcomes.

The purpose of this honors thesis was to determine pediatric healthcare providers' perception of health literacy in their practices. A qualitative descriptive design was used to compare perceptions of a pediatric nurse practitioner, a family nurse practitioner, and a pediatrician. The findings were analyzed in order to make suggestions regarding how providers might impact pediatric health outcomes by understanding the level of health literacy of caregivers. Comparing medicine and nursing will provide evidence to help reconcile the gaps in the pediatric interprofessional team in order to improve patient-centered care.

LITERATURE REVIEW

Health literacy must be assessed and addressed because it influences so many aspects of a person's health. Low health literacy affects many areas of healthcare and can lead to unfavorable outcomes. Patients with low health literacy may not be able to adhere to treatment regimens, which decreases the benefit of the therapy (Healthy People, 2020). Lower health literacy is correlated with more frequent emergency room visits (Healthy People, 2020). While there is a great deal of research conducted on the health literacy levels of adults and its influence on health status, there is a limited amount of research conducted on the impact of low health literacy in pediatric populations.

Several assessment tools, such as the Rapid Estimate of Adult Literacy in Medicine (REALM), the Test of Functional Health Literacy in Adults (TOFHLA), and the Newest Vital Sign (NVS), are used to assess the health literacy level of adults. However, a newer tool, the Parental Health Literacy Activities Test (PHLAT), is directly targeted at the health literacy of adults who are also parents or caregivers. This 20-item scale specifically focuses on the caregivers of infants (birth to 1 year of age). Domains covered with the PHLAT include nutrition/growth/development, injury/safety, and medical/preventive care. The tool contains these domains to assess both literacy and numeracy skills (Kumar et al., 2010). The aforementioned domains and skills are essential for a caregiver to have in order to meet the basic health needs of the child.

Kumar et al. (2010) conducted a study to validate the PHLAT and its results. Participants were obtained through convenience sampling from three pediatric clinics at academic institutions (Kumar et al., 2010). In order to be considered for the study, the

participant had to be a caregiver of an infant 13 months old or younger and speak English. Those with severe visual impairments or psychiatric illnesses were excluded from the study (Kumar et al., 2010). A total of 182 participants were assessed, and the primary reason for those that declined participation was lack of time (Kumar et al., 2010). Most of the participants were mothers (86.7%) with high school or equivalent education level (42%) (Kumar et al., 2010).

The researchers found that one in four participants could not properly prepare medication doses or read a digital thermometer, while half of the participants could not prepare over the counter medication or interpret a growth chart. Seventy-five percent of participants could not analyze a breastfeeding brochure. Scoring higher on the PHLAT was directly correlated with higher educational level as well as higher numeracy and literacy skills. While this tool is excellent for assessing parental health literacy, it is very time-consuming to administer. The tool took an average of 21 minutes to administer in the study (Kumar et al., 2010). A shortened version, the PHLAT-10 in English and Spanish, is in the process of further validation according to Kumar et al. (2010).

It is clear that low health literacy is a tremendous problem in the United States based on the results of the NAAL (Kutner et al., 2006). While some factors that impact health literacy cannot be changed, one risk factor that can be altered is how the healthcare providers adapt their care and teaching to meet the needs of low health-literate populations. The Healthy People 2030 updated definitions of health literacy acknowledge that personal health literacy is contextualized based on organizational health literacy (HHS, 2020). Unfortunately, it is unclear how much validated health literacy screening tools are used in pediatric primary care practice because there is only one tool to assess

pediatric caregiver health literacy (Kumar et al., 2010). Therefore, it may be up to the provider to make a judgment call on the necessary health teaching needed for each patient based on their assumptive health literacy level. Currently, a universal precautions approach is recommended by the Nation Action Plan to Improve Health Literacy (2010) that is referenced within the Healthy People 2030 definitions of health literacy.

Harrington et al. (2013) explored the consistency between pediatric provider perception of health literacy and subsequent teaching modalities used regarding asthma treatment. The providers' perception of health literacy level was compared with the validated health literacy level of the parents as assessed by TOFHLA and REALM. In this study, the providers were found to have judged health literacy level based on the parent's ability to carry out treatment recommendations and altered their teaching based on how they perceived the parent's health literacy (Harrington et al., 2013).

Providers' perceptions of parental health literacy were often inconsistent with the actual score as seen on the TOFHLA and the REALM. Regarding TOFHLA, providers were consistent with the tool's score 65% of the time, while providers rated the participant higher than the actual score 4.3% of the time. In comparison, REALM scores indicated that providers were consistent with the tool's score 49.8% of the time and rated participants higher than their actual scores 32.5% of the time (Harrington et al., 2013). Factors that led the providers to rate the participant's health literacy levels higher were higher education level and higher income. The researchers also found that providers tended to rate the health literacy of Caucasians higher when compared to African Americans. In addition, Harrington et al. (2013) noted that whenever providers interpreted that a parent had low health literacy, they simplified their teaching. Providers

reported giving reduced amounts of information to the patients with perceived low health literacy and asking these parents to repeat back what they had been taught in "your own words" (Harrington et al., 2013, p. 72).

While the aforementioned study explored the accuracy and consistency of perception regarding health literacy among providers related to asthma treatment, Harrington and Keehner Engelke (2016) utilized an online survey tool to explore the perception of health literacy in practice among pediatric nephrology interprofessional team members from across the United States. Physicians or advanced practice providers comprised 32 of the 147 respondents; other disciplines surveyed included but were not limited to registered nurses (52%), registered dieticians (13%), and child life specialists (3%) (Harrington & Keehner Engelke, 2016).

Eighty-nine percent of participants in the study recognized the importance of conducting health literacy assessments, and 92% of them were open to performing the assessments. Sixty-nine percent of participants reported that they were not currently using a tool to assess health literacy, and 67% felt that they could assess health literacy with other modalities. While the subjects recognized that low health literacy is a problem, reported barriers to addressing the issue included lack of time and resources to conduct health literacy assessments as well as lack of confidence in approaching the parent of a pediatric patient regarding his or her low health literacy (Harrington & Keehner Engelke, 2016). Overall, the study demonstrated that members of the pediatric nephrology interprofessional team recognized health literacy as a concern. They indicated the desire to learn more about health literacy, but they felt limited by their lack of training regarding the topic. The team members articulated that communication between team members

would be strengthened if health literacy was addressed collaboratively (Harrington & Keehner Engelke, 2016). The desire for knowledge about health literacy and the lack of available resources to promote health literacy in practice is a conflict that needs to be addressed.

When providers can effectively assess health literacy, they have the skill and knowledge base to adapt their care; however, concern arises when their assumptions are not consistent with the actual health literacy level of the patient. Caregivers and pediatric patients may receive information that is too advanced for them, or they may be given information that is extensively simplified to the point of missing important details.

In conclusion, it can be concluded that low health literacy can negatively impact health outcomes, and clinicians are not always provided education on the best way to assess and address low health literacy. Utilizing and implementing a universal screening approach can be varied among providers and may be skewed by barriers such as lack of time. There is a gap in the literature regarding health literacy in the pediatric primary care setting. Pediatric patients and their caregivers may have the opportunity to visit the same primary care setting until the child reaches adulthood, so it is vital that health literacy is assessed, as implications will carry beyond one single visit. Finally, although previous tools have surveyed various specialized pediatric providers, there is a gap in the literature regarding the lived experience of pediatric primary care providers as they grapple with best practice regarding health literacy.

METHODOLOGY

The purpose of this qualitative descriptive study was to determine pediatric healthcare providers' perceptions of health literacy in their practices. To begin, background information on the current state of health literacy was obtained by searching reputable government websites (CDC, HHS, Healthy People 2020/2030). Then, a literature review was performed utilizing the Western Kentucky University (WKU) Libraries Databases using the keywords *provider perception, pediatrics,* and *health literacy*. Reviewing the literature guided the development of interview questions. The research question for this honors thesis was: In the pediatric primary care setting, what is the provider's perception of the impact of a caregiver's level of health literacy on the health outcomes of a pediatric patient? Data was collected qualitatively through interviews conducted utilizing a video conferencing platform. The research received approval from the Western Kentucky University Institutional Review Board (IRB) prior to data collection.

Participants were obtained through purposive sampling. In order to be considered for the interview process, participants had to be pediatricians or nurse practitioners having practiced in a pediatric primary care setting within the last year. Participants were recruited via email or phone. All participants electronically signed an IRB-stamped informed consent document (see appendix).

After consenting to an interview, the healthcare provider joined a Zoom meeting with the student researcher and at least one thesis advisor. The student researcher and thesis advisor joined the interviews in locations where audio from the interview would

remain confidential. Interviews were recorded, transcribed, and analyzed for common themes. The following IRB-approved questions were asked during each interview.

1. Please briefly tell me about your credentials and your practice.
2. How would you define health literacy?
3. Do you feel like the population you serve demonstrates low health literacy?
4. What methodology do you use, if any, to determine the health literacy of your patients and their parents?
5. Are you familiar with tools such as Parental Health Literacy Activities Test (PHLAT), Newest Vital Sign (NVS), or Rapid Estimate of Adult Literacy in Medicine (REALM) to screen for health literacy?
6. How big of a problem do you believe low health literacy presents in the healthcare field?
7. How do you believe that this impacts the health outcomes of your pediatric patients?
8. What materials do you use (printed, audio tapes, videos, etc.) when teaching your patients?
9. During your undergraduate and graduate schooling, were you taught the principles of health literacy and assessment of it?
10. Would you be willing to learn more about the topic now if opportunities were presented to you?

Additional questions were asked if the interviewee's response presented the need for more information to be elicited. Although the research is primarily qualitative, closed-

ended questions such as numbers three, five, nine, and ten were analyzed quantitatively as well for easier interpretation of data.

DATA ANALYSIS

After the three interviews were transcribed using Microsoft Word, the interviews were read multiple times by the student researcher in order to achieve data immersion. Next, the data from the interviews was analyzed and placed in a chart based on the participant and their responses to each of the questions. From there, interviews were searched for key quotes that were added to the chart. Finally, the three interviews were compared for common themes. The student researcher sent the transcripts, analysis, and themes to the faculty thesis advisor to confirm validity of the data analysis.

RESULTS

The total number of participants in the interview process was three (n = 3). The sample consisted of two nurse practitioners (NP) (n = 2) and one pediatrician (n = 1). Participant one was a pediatric nurse practitioner (PNP) with over 40 years of experience in her role. She had practiced in public health and in developmental/genetic disorder clinics, but the majority of her experience has been as a PNP in a primary care setting. Participant two was a family nurse practitioner with a master's degree in nursing education. Participant two differed from participant one and three because, although she prefers to see pediatric patients, she cares for both adults and children in her primary care practice. Participant three was a pediatrician in private practice who also oversees clinical rotations for third year medical students.

Health Literacy Level in Their Practices

Participants were asked whether they felt their population demonstrated a low level of health literacy. While a yes or no response was expected for this question, the participants included more specific information to clarify their responses. Participant one described the health literacy of the population she served as adequate, while participant two and three explained that the populations they served have variable health literacy.

Despite approximately half of her patient population being non-English speaking, participant one felt her patients had adequate health literacy. This PNP felt the caregivers asked good questions whether they spoke English as their first language or not. She did report, however, that her patients may not have good health literacy when "compared to a private practice where you have lots of professional parents that are very well-educated."

The group she identified as having a low level of health knowledge was teen mothers. Because these mothers are still pediatric patients themselves, they often depend on their caregivers to assist in making healthcare decisions for them and therefore are subject to the consequences of their caregiver's health literacy level.

Participant two reported a variety of health literacy levels in the population she worked with and felt it was difficult to generalize the population's health literacy. She stated that her patients make up all stages of life and all educational levels. Her population covers a wide range of patients, from those that are new to the United States who may have never had access to health materials before to well-educated patients who are now retired and in need of medical care. When discussing the pediatric caregivers she interacts with in her practice, she stated, "My peds parents are more motivated to learn and to learn the right way to care for their children than maybe an adult is [to learn] caring for themselves."

Participant three reported that health literacy varies within her population, and she is often surprised by people who have a low health literacy level that do not seem to. Despite feeling as if most of her population demonstrates sufficient health literacy, she assumes everyone has poor health literacy. Two consistent factors that participant three believes impact health literacy are how sick the child is and subsequently how much the caregiver has slept. Finally, participant three mentioned extraneous variables can lead to decreased retention of health information by taking the caregiver's focus away from the visit. Oftentimes, these disturbances are not revealed to the provider. Participant three stated that she will call the parent and follow up that evening after the visit if she is particularly worried about a caregiver and their lack of understanding.

Familiarity with Health Literacy Screening Tools

The researcher asked participants if they were familiar with several common tools used to assess health literacy including the PHLAT, NVS, and REALM. None of the participants were familiar with these tools. Participant two was curious about the tools, but, when the details of the tools were provided to her, she stated, "I'm not sure that would work with my population." Participant three brought up that there are several tools that pediatricians are expected to use at each wellness checkup, but she has found that a lack of time is a major barrier to utilizing them.

Previous Education on Health Literacy

None of the participants recalled receiving formal teaching about health literacy in their undergraduate and graduate programs. However, they all recall learning information that relates to the principles of health literacy, but it may not have been explicitly called health literacy. Participant one explained that a "big focus" in her nurse practitioner program was "being able to target the mothers that needed more education." Her program provided "the counseling and whatever tools that I [participant] needed to help a mother understand." Participant two noted that she was instructed on gathering baseline data about a caregiver's health literacy through the history taking process. Participant three recalled learning that patients may not always understand the health information that is presented to them.

Willingness to Learn More

Participants were asked about their willingness to have further training related to health literacy screening. Both NPs expressed interest about the topic, while the pediatrician was not as eager to learn.

Participant one expressed that she is "always open to anything that's going to help a parent take better care of their child." She desires to utilize a tool that would better assess health literacy but recognizes time as a barrier to proper assessment of health literacy. Her desire is for the assessment and intervention to be quick. She cited an example of having to see 20 patients in four hours, which leaves little room for extensive, additional assessments regarding health literacy. She believes that nurse practitioners would be more prone to utilize the tool when compared to pediatricians.

While participant three believes that health literacy is something society as a whole should work on, she is not personally interested in learning about the topic because she feels her emotional intelligence and ability to care transcends the benefit of obtaining more information about health literacy. She explained, "People don't care how much you know if they don't know how much you care."

Personal Definition of Health Literacy

When asked to define health literacy, participant one stated, "how much a parent is aware of what's involved to keep their child healthy." She explained that you can get a solid foundation of the parent's awareness through conversations with the parent. Participant two stated that health literacy is a person's knowledge and understanding of not only what it is to be healthy but also the knowledge of resources and medical care that are available to them. Participant three defined health literacy as the ability to receive and apply either verbal or written instructions. She postulated that patients that have good health literacy will be able to follow the instructions that healthcare professionals give them, while patients that have poor health literacy will struggle when trying to follow instructions provided. An aspect crucial to applying health literacy skills highlighted by

participant three was the understanding of the final goal of treatment and what steps were necessary to ensure the patient obtains that goal.

Health Literacy Screening in Personal Practice

Assessment of health literacy varied among participants in the study. Participant one believed that a provider can determine a parent's health literacy level through history taking. For example, if a parent came into the clinic and the chief complaint was that the child's temperature was 103°F overnight, then the clinician should ask how the parent knew that the child's temperature was extremely elevated. Answers such as, "Well, they felt really hot," may demonstrate an improper understanding of the child's health status, but a parent who explains that he or she took the child's temperature as instructed may have a better understanding of the child's health status. Further validation of proper health literacy can be obtained through assessing the caregiver's understanding of the treatment of a high fever.

To determine the health literacy of caregivers of pediatric patients, participant two obtained information through the conversation with the caregiver during the review of systems (ROS). In the healthcare profession, a pediatric ROS is conducted by asking the caregiver a series of questions about each body system in order to identify and clarify any signs and symptoms that the pediatric patient is experiencing.

Participant three assesses the compliance of the parent. If the child is doing well, she will not delve into the parent's health literacy level. From her perspective, good health literacy is correlated with the ability to effectively follow through with provided instructions that are intended to improve patient outcomes. If there seemed to be an issue with compliance, however, participant three investigates the situation further to determine

health literacy. Through her experiences, she has found that caregivers may often seek to please the provider and say that they followed through with health instructions, regardless of whether they did or did not. To prevent this occurrence, participant three asks the pediatric patient about how the instructions were carried out.

Concerns about Health Literacy in Healthcare

Participant one did not address the healthcare field as a whole, but she did bring up valuable points regarding her practice that can be applied to low health literacy in the healthcare field. She discussed that not properly understanding health information leads caregivers of pediatric patients to incorrectly carry out instructions.

Participant two believed that low health literacy presented a "big problem" in the healthcare field. Although people may feel as if they have a good understanding of their health and how to manage it, the information that they have may not be correct, or in participant two's words, "may not be productive or valid." She specifically noted that the issue of low health literacy has a great impact on her pediatric patients.

Participant three had a slightly different perspective from the other participants but she also focused more on her practice than the healthcare field as a whole. She found that low health literacy of pediatric caregivers does not have as large of an impact as it would in adult acute care. She explained that this is because most of the conditions treated in the pediatric primary care setting are viral and are self-limiting. Participant three stated that health literacy plays more of a role in pediatric health outcomes if the pediatric patient is suffering from a disease that requires chronic management, such as asthma or eczema. When guiding a patient through the management of chronic disease, participant three explained that health literacy probably only accounts for 50% of the

achievement of positive health outcomes. She elaborated by stating that the other half is the caregiver understanding why the treatment plan is being initiated and that the patients and parents must also be keenly aware that you care about them and the well-being of the child.

Impact on Health Outcomes in Patients

Because participant one cares for a diverse population of patients, she stated that the impact of low health literacy on health outcomes is affected greatly by cultural differences. In her patient population, she believed that nonadherence to medication regimens arose from cultural differences between her population and the practices of Western medicine utilized in the United States. Those patients that immigrated from a different country had difficulty trusting the healthcare system in the United States. Their mistrust led to a poor understanding of the purpose of treatment therapies and lack of confidence that the treatment options would achieve the desired outcomes of optimal health and well-being. She also found that those who could read English had better health outcomes related to greater adherence to instruction as a result of being able to take a written instruction home with them. In participant two's practice, she noted that information passed down from generation to generation was often not completely accurate and led to treatment decisions made by the caregiver that would impact the pediatric patient. As previously mentioned, participant three found that low health literacy had a greater impact on the health outcomes of pediatric patients suffering from chronic disease.

Materials Used in Patient Teaching

All participants reported teaching with verbal and written instructions. Participant one found that those who could read English had better health outcomes related to greater adherence to written instructions they could take home with them. Participant two stated that she mainly utilized printed materials. She provided computer-generated handouts to the parents based on the age and developmental stage of the child. She reiterated that it was rare for a pediatric patient to leave the clinic without a handout. Participant two found that caregivers of pediatric patients were often more motivated to learn and better manage their health when compared to adults who are only learning health information in order to better care for themselves. Participant three utilized a combination of verbal and written instructions to teach her patients. When there was a question as to whether the parent understood the instructions, participant three asked the parent to relay the information back to her. Her handouts were either preprinted or personally written by her. She specified that at every well child checkup, the parent was given a handout with preprinted instructions for that particular visit. She stated that videography is the gold standard for teaching patients. From her perspective, if the provider can be filmed and watch himself or herself, the provider has a better opportunity to assess the effectiveness of the teaching.

DISCUSSION

A common denominator seen in all three of the interviews was obtaining health literacy levels through conversations with caregivers. The providers then determined the health literacy levels of the caregivers based on their ability to follow verbal and written instructions. Participants identified correcting caregivers in a caring and nonjudgmental manner as the primary way to improve health literacy.

Common barriers to proper health literacy described by the participants include lack of sleep, language barriers, and cultural barriers. Organizational health literacy is disrupted by the time constraint of a fast-paced healthcare setting. None of the participants provided an absolute "yes" or "no" when asked if their populations demonstrated low health literacy; it was reported that there was a mix of health literacy levels throughout each practice, and it sometimes surprised the provider as to who had higher levels of health literacy and who had lower levels. All participants reported discrepancies in health literacy and competency when they assessed the ability of caregivers to complete simple tasks of nutrition and medication administration. Perceived low health literacy by the provider was correlated with the caregiver's inability to carry out instructions provided.

None of the participants were familiar with tools that can be utilized to assess health literacy, and none of the participants were directly taught about the principles of health literacy in the academic setting. Both nurse practitioners were willing to learn more about the topic, but the pediatrician was not interested, although she recognized that

it is an important issue that the medical community as a whole should focus on improving.

Limitations

Although this study provides valuable insight into the lived experience of pediatric healthcare providers, several limitations arose throughout the research process. The design of this study had to be significantly altered due to it being conducted during the COVID-19 pandemic. Semi-structured interviews were conducted on a video conferencing platform, and participant recruitment was difficult. The healthcare community was burdened already with the consequences of the pandemic and potential participants did not have excess time to participate in research. Although commonalities were identified, data saturation was not reached due to the lack of participants.

Participants came from vastly different clinics, so their experiences were varied. The data was not similar enough to draw solid generic conclusions about the pediatric primary care setting. Additionally, all participants practice in a rural community, so the results found in this qualitative descriptive study may not apply to geographic locations with a different demographic. All of the providers interviewed were female and had been practicing for over 20 years; therefore, no male perspective or new graduate perspective was provided. The lack of new graduate providers may have altered the results because health literacy is now currently being taught in undergraduate healthcare programs.

Implications for Practice

By looking at current literature and learning from the perspectives of the three healthcare providers that were interviewed, there is no doubt that low health literacy is a concern in pediatric healthcare. The lack of knowledge about healthcare instructions and

how to carry them out can lead to poorer outcomes. Therefore, healthcare providers should be cognizant of the way they are presenting health information. Through the use of a universal screening for health literacy, the healthcare professional can ensure that no information is being presented above the level that the caregiver understands. Another method to assess caregiver understanding, as cited by the literature and interviews, is the teach back method. The teach back method involves asking caregivers to repeat the information presented in their own words. By utilizing the teach back method, the healthcare professional can rapidly assess the patient's or caregiver's understanding of the material presented. As a result of utilizing the teach back method during the initial teaching session, health outcomes can be improved as the provider immediately becomes aware of the patient's understanding of the instructions provided. Adhering to this practice allows the provider to avoid the situation of waiting until the next visit to determine health literacy. At that point, missed instructions may have already led to poorer health outcomes due to noncompliance.

CONCLUSION

In conclusion, health literacy is a major issue that affects all people, regardless of age, race, socioeconomic status, or educational level. Healthcare providers must take responsibility for determining the health literacy of their patients and adjust teaching methods to meet the needs of the patient or caregiver. In addition, caregivers of pediatric patients must take responsibility for managing their child's health to the best of their abilities.

The perspectives provided in this study give a voice to the literature that points to the need for improved health literacy in pediatric healthcare settings. The healthcare system can be intimidating to patients, especially if they have barriers to understanding health information. The healthcare provider should never neglect assessment of the patient or caregiver's understanding of provided health information. Health information can be presented in a way that prompts a desire in the patient to collaborate with the provider to achieve the best health outcomes. Better health outcomes in the pediatric primary care setting leads to healthier and happier kids.

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APPENDIX

INFORMED CONSENT DOCUMENT

Project Title: Parental Health Literacy: Comparing Perceptions of Pediatricians and Nurse Practitioners
Investigator: Kirbey Flora, WKU School of Nursing Student Nurse, kirbey.flora227@topper.wku.edu
Faculty Advisor(s): Dr. Dawn Garrett-Wright and Dr. Liz Sturgeon, (270) 745-3800

You are being asked to participate in a project conducted through Western Kentucky University. The University requires that you give your signed agreement to participate in this project.

You must be 18 years old or older to participate in this research study.

The investigator will explain to you in detail the purpose of the project, the procedures to be used, and the potential benefits and possible risks of participation. You may ask any questions you have to help you understand the project. A basic explanation of the project is written below. Please read this explanation and discuss with the researcher any questions you may have. If you then decide to participate in the project, please sign this form in the presence of the person who explained the project to you. You should be given a copy of this form to keep.

1. **Nature and Purpose of the Project:** The purpose of this project is to compare the perceptions of pediatricians and pediatric nurse practitioners concerning parental health literacy. Data collected during the interviews will aid in the United States' continuing goal of improving health literacy by helping propose a solution to bridging the gap between the pediatric interprofessional team. It is the researchers' hope that, through this project, health teaching may be modified to better serve parents and caregivers making health decisions for pediatric patients.

2. **Explanation of Procedures:** Data for this study will be collected through interviews. If you consent, you will be asked to select an interview time that best fits your schedule; interviews will be conducted via Zoom meetings. Both the student investigator and at least one faculty advisor will be present on the recorded meeting. The meeting will take approximately 20 to 45 minutes of your time. Audio from the meetings will be transcribed and used in the research paper without direct identifiers.

3. **Discomfort and Risks:** Risks for participation are minimal. Participating in the interview may take approximately 20 to 45 minutes of your time. Questions asked by the student researcher may require you to admit shortcomings in your practice, which may make some healthcare professionals uncomfortable.

4. **Benefits:** The benefits of this study for the participants include:
   1) The opportunity to evaluate one's own current practice.
   2) The opportunity to learn more about current best practice regarding health literacy and tools used to assess health literacy.

Overall, this study will benefit future pediatric primary care practice by displaying how health literacy is currently utilized and how practices can be utilized in the future to better improve care of pediatric patients.

WKU IRB# 21-027
Approved: 9/01/2020
End Date: 5/31/2021
EXPEDITED
Original: 9/01/2020

(Revised August 2018)

5. **Confidentiality:** All interviews will be coded with non-identifying information. Audio recordings will be transcribed, and any identifying information will be omitted from the final research paper. All interviews, data, and information will be kept on the student researcher's password-protected computer. Data gathered from this project will be kept in a locked cabinet located in the faculty's sponsor's office for a minimum of 3 years.

6. **Refusal/Withdrawal:** Refusal to participate in this study will have no effect on any future services you may be entitled to from the University. Anyone who agrees to participate in this study is free to withdraw from the study at any time with no penalty.

You understand also that it is not possible to identify all potential risks in an experimental procedure, and you believe that reasonable safeguards have been taken to minimize both the known and potential but unknown risks.

_____ _____
Signature of Participant Date

_____ _____
Witness Date

- I agree to the audio/video recording of the research. ***(Initial here)*** _____

THE DATED APPROVAL ON THIS CONSENT FORM INDICATES THAT
THIS PROJECT HAS BEEN REVIEWED AND APPROVED BY
THE WESTERN KENTUCKY UNIVERSITY INSTITUTIONAL REVIEW BOARD
Robin Pyles, Human Protections Administrator
TELEPHONE: (270) 745-3360

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