

Providers' Perspectives on Patient Health Literacy in the Rural Deep South

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Abstract

Introduction: Alabama is a largely rural state and is ranked 48th in health outcomes among all states in 2020. Although health literacy is essential to improve patient outcomes, health literacy assessments are not routinely incorporated into the medical setting. The purpose of this study is to explore perspectives on health literacy from primary care providers in the rural deep South and the use of health literacy assessments. These assessments help providers evaluate their understanding

of their patients' literacy levels and their adapting methods to foster the best health outcomes for their patients.

Participants: The study population consisted of twelve healthcare professionals serving patients from five rural communities in Alabama. These healthcare professionals included eight (67%) physicians and four (33%) nurse practitioners.

Results: Many providers in this study reported not having a formal method of assessing patients' health literacy status. Instead, most used their judgment or surrogate methods (e.g., reading office brochures) to determine patients' ability to perceive the information presented to them and use it to manage their health.

Conclusions: Healthcare providers must consider assessing health literacy simply and uniformly. For example, using newer health literacy measures that are valid and easy to use could provide helpful information about patients' ability to comprehend and use health information. Additionally, social support networks and/or health care advocates should be considered as an intervention to address health illiteracy.

Keywords: Health literacy, Primary Care, Rural, Social networks, Healthcare Advocates, Health Providers

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Healthy People 2030 defines health literacy “as the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others” (Office of Disease Prevention and Health Promotion, n.d. section 3). Many factors contribute to a patient's overall health literacy, including educational attainment, income, age, race, ethnicity, gender, and language. Research by the Milken Institute (Lopez et al., 2022) suggests that numerous surveys and evaluations have demonstrated a

substantial correlation between adult health literacy and other factors contributing to health inequalities. Language ability, age, gender, race/ethnicity, religion, and socioeconomic level influence how people engage with the healthcare system. Health inequalities can be caused by cultural disconnects between the person and the healthcare system, which can show inadequate health literacy. "Only 12% of US adults are proficiently health literate; at least 88% lack the health literacy necessary to use the healthcare system and advance their well-being (55 percent intermediate proficiency, 22% basic proficiency, and 14% below basic proficiency)" (Lopez et al., 2022, p. 8).

Healthcare is expensive, and the cost is amplified in rural communities as the poverty rate is higher for individuals who reside in rural communities (Shah et al., 2010). Patients with low socioeconomic status spend a disproportionate amount of yearly income on healthcare (Coulter & Collins, 2011). On average, a patient with improved health literacy spends \$700 less on health care than a counterpart with low health literacy (Weiss et al., 2005). Low health literacy adversely affects patient health and has a negative financial impact on the healthcare system. Individuals with limited health literacy sometimes struggle to read medication labels, follow doctor's advice, participate in medical decision-making, and show up for follow-up appointments.

Moreover, people with low or marginal health literacy frequently struggle with poor self-care practices, get fewer preventative treatments, and die from all causes at higher rates (Shahid et al., 2022). According to Shahid et al. (2022), individuals with low health literacy may use more resources, frequent emergency room and inpatient treatment, pay more for their care, and experience worse health outcomes. Berkman et al. (2011, as cited by McDonald & Shenkman, 2018, p. 2) discovered that "low health literacy was consistently associated with more hospitalizations, greater use of emergency care, lower receipt of mammography screening and

influenza vaccine, poorer ability to demonstrate taking medications appropriately, poorer ability to interpret labels and health messages, and among elderly populations than those health status and higher mortality rates.” Individuals with low health literacy are linked to more visits to the emergency room, more hospitalizations, and longer hospital stays than similar individuals with a higher health literacy score (Griffey et al., 2014; Berkman et al., 2011). Low health literacy significantly impacts the health system, costing the United States economy between \$106 billion to \$238 billion annually (Vernon et al., 2007).

Groups with lower average literacy proficiency scores include those who are poor, members of ethnic and cultural minorities, those who live in southern and western regions of the United States, those with less than a high school degree or GED, and those who are above the age of 65 (Institute of Medicine Committee on Health Literacy et al., 2004). Educational and health disparities underlie these group differences. African American adults are more likely to have below basic and basic literacy levels, at 58%, compared to all other race/ethnic groups (Muvuka et al., 2020). In Alabama, up to 59% of adults are categorized as having low levels of health literacy (National Center for Education Statistics, 2003 as cited by Muvuka et al., 2020). Alabama is a largely rural state and was ranked 47th in health outcomes among all states in 2020 (United Health Foundation, 2022).

Although health literacy is essential to improve patient outcomes, health literacy assessments are not routinely incorporated into the medical setting (Shah et al., 2010; Hersh et al., 2015). Furthermore, studies show that many healthcare professionals are unaware of the prevalence of limited health literacy, and patients routinely overestimate their patients' ability to understand and react to medical information (Jukkala et al., 2009; Kelly & Haidet, 2007).

This study was to explore healthcare providers' use of health literacy assessments in clinical practice, their communication with patients about cancer screening, and any adaptations made to foster the best health outcomes for their patients. This study specifically focuses on healthcare providers who treat predominantly African American patients in rural Alabama because, as aforementioned, this subset of people tends to have lower health literacy and poorer health outcomes.

Methods

Research Design

An exploratory qualitative study was conducted and included semi-structured interviews with 12 primary healthcare providers serving predominantly rural patients. This study was part of a more extensive study focused on cancer screening (Hooper et al., 2017; Oliver et al., 2018). For this study, "rural" was defined using the United States Department of Agriculture (n.d.) 2013 rural-urban-continuum codes. The complete interview included 18 questions on a range of health topics. Seven questions were selected explicitly because they pertained to health literacy. Semi-structured interviews are a standard method in qualitative research preferred due to its versatility and flexibility (Kallio et al., 2016). The semi-structured interview combined with qualitative content analysis was chosen because it offers uniformity by giving the interviewer a specific set of questions and analysis that remains close to participants' responses (Sandelowski, 2000; Russell & Gregory, 2003). The flexibility of these interviews accommodated follow-up questions that yielded rich data from participants.

Study Population

The United States Census Bureau defines a rural area by exclusion. To be classified as a rural area, the population is under the required threshold for an urban area or urban center. An Urbanized

Area is defined as having a population of 50,000 or more while urban clusters have a population of at least 2,500 and less than 50,000 (Lancaster et al., 2014). According to the 2010 USCB data, 55 of the 67 Alabama counties do not have the population to be defined as an urban county (Musemwa & Gadegbeku, 2017). Of the 4,658,782 people in Alabama, 2,031,229 (43.6%) of the population live in rural areas (Musemwa & Gadegbeku, 2017).

The study population consisted of 12 healthcare professionals serving patients from Tuscaloosa County (25% rural) and four rural communities in Alabama. These healthcare professionals included (67%) physicians and (33%) nurse practitioners. The age range of the rural providers was 30-66 years old, with a mean age of 47 years old. The racial demographic consisted of (75%) African American providers, (17%) Non-Hispanic White providers, and (8%) Asian provider. Of the providers interviewed, (67%) were females and (33%) were males. One healthcare provider practiced in Greene County (8.3%), two practiced in Hale County (16.6%), one practiced in Pickens County (8.3%), five practiced in Sumter County (41.7%), and three practiced in Tuscaloosa County (25%). According to the West Alabama Regional Commission (n.d.), Tuscaloosa County is the epicenter of a seven-county region designated as West Alabama. All six other surrounding counties are designated as rural counties. It is important to note that providers in Tuscaloosa County treated many patients from rural areas, as these patients were willing to drive to Tuscaloosa for care. Relevant characteristics of these Alabama counties are included in Table 1, and the demographic characteristics of the study participants are presented in Table 2.

Table 1*Characteristics of Study Counties*

Location	Population	Median Household Income	Poverty Rate	Percent lacking basic prose literacy skills*	Racial Diversity According to the 2020 Census	
					Caucasian	African-American
Alabama	4,903,185	\$50,536	15.50%	15%	65.35	26.6%
Greene	8,111	\$24,145	31.70%	31%	17.01%	79.6%
Hale	14,651	\$21,191	20.50%	26%	39.83%	58.95%
Pickens	19,930	\$39,848	24.30%	21%	53.8%	40.01%
Sumter	12,472	\$24,320	36.40%	28%	24.2%	75%
Tuscaloosa	209,335	\$53,236	16.20%	14%	49.3%	49.3%

*Those lacking basic prose literacy skills include those who score below basic in prose and those who could not be treated due to language barriers. Reference: U.S. Census Bureau (n.d.); Percent lacking basic prose literacy skills (National Center for Education Statistics. 2003).

Table 2*Characteristics of Study Participants (n = 12)*

Characteristics	n (%)
Healthcare Occupation	
Physician	8 (67%)
Nurse Practitioner	4 (33%)
Age (mean years)	47; range 30-66
Race	
African American	9 (75%)
Non-Hispanic White	2 (16.7%)
Asian	1 (8.3%)
Gender	
Female	8 (66.7%)
Male	4 (33.3%)
Practice Location	
Sumter County	5 (41.7%)
Tuscaloosa County	3 (25%)
Hale County	2 (16.7%)
Pickens County	1 (8.3%)
Greene County	1 (8.3%)

Data Collection

Face-to-face interviews where written consent was obtained prior to the interviews according to the research protocol approved by the University of Alabama Institutional Review Board. No identifying participant information was attached to the individual recordings, and all data were securely maintained. A \$50 incentive was offered to each participant.

Questions

The selected semi-structured interview questions are presented in Table 3. Seven relevant questions were asked to each of the participating providers related to health literacy and the scope of this study. Research questions driving the qualitative inquiry included questions about the patient populations, common medical conditions, as well as providers' perceptions of the state of health literacy in the selected rural communities. Interviews also explored healthcare providers' adaptation to patients' literacy levels in the provision of care.

Table 3.

Semi-Structured Interview Guide

1. What is the patient population seen in this clinical setting?
2. In your practice, how do you share the decision-making process?
3. What is the most prevalent medical problem seen in your clinic?
4. Are the patients seen in this clinical setting assessed for health literacy?
5. What tools are you using to assess a patient's health literacy?
6. How do you respond to patients who appear overwhelmed or do not understand the health information provided?
7. Some healthcare providers have reported that they are seen by patients as authoritative figures, and patients tend to agree with what is said to or asked of them. What are your thoughts in regard to this among the patients seen in your clinic?

Data Analysis

The audiotaped interviews were transcribed verbatim, and analyses was facilitated via NVivo 12.0 (QSR International, 2017) qualitative analysis software. The interviewer and researchers

reviewed the transcripts for accuracy. The best standards of qualitative methodology that support validity are rigor, trustworthiness, and awareness of reflexivity, credibility, and believability (Thorpe & Holte, 2007). In this study, we increased the trustworthiness of our findings by directly examining reflexivity, or what the coder brings to the coding of qualitative data, through investigator triangulation. Two authors (JSO and RSA) independently reviewed the transcripts of each interview and identified themes from the participants' responses. The two authors then compared the themes and organized the data into categories. This investigator triangulation helped to keep investigators aware of potential biases and facilitated solid evidence for interpreting the data (Sandelowski, 2000). Discrepancies were infrequent and were discussed until a resolution was achieved. The analysis team kept detailed notes as part of an audit trail (Thorpe & Holte, 2007).

Results

Participants' responses capture the variance and similarities related to the health literacy of the patients to whom they provide care. Responses allow insight into the patients encountered and their common medical conditions, the decision-making process between rural providers and patients, how health literacy is assessed, and the role health literacy plays in patient-physician interaction.

The rural providers generally treated a diverse patient population in regard to race and age. The majority of the providers surveyed, 66% (8/12), described their patient population as largely African American. The rural healthcare providers also specifically mentioned providing care to older populations and those from a low socioeconomic background. Of the healthcare professionals interviewed, 33% (4/12) explicitly stated that their patient population is from a low socioeconomic background.

The prevalent medical conditions in the responses were hypertension, diabetes, and obesity. While each participant cited obesity, some participants mentioned it first, then described obesity as a contributing factor to other diseases, namely diabetes and hypertension. The participants discussed how these chronic conditions are interconnected and that this triad of problems often occurs simultaneously in their patients.

The qualitative responses are uniform and reflect epidemiological data demonstrating the prevalence of the conditions in rural, predominantly African-American patient populations. The findings underscore the significance of providers promoting health literacy among their patients, making it easier for providers to recommend behavioral health treatments for these diseases, in ways that patients can comprehend. Many of the treatment recommendations for the conditions require behavior change as well as adherence to a medication regimen.

The Shared Decision-Making Process

The rural providers were asked about the process of decision-making in their clinical practice. A slight majority of the practitioners specifically described employing the shared decision-making process, in which the patient is involved in the decision of their care.

Of the rural providers interviewed, 54% (6/11) specifically reported that they engaged in a shared decision-making process, where they gave patients information and allowed them to decide how to move forward.

Shared decision-making is me telling the patient, “This is what the recommendations are. This is why I believe you should have it. In the end, it is your choice, because you have a sound mind to make the decisions that are best for you, but I strongly suggest that we go ahead and try to get this screening done.” So, my shared

participation is giving them the information but in the end still letting it be their choice.

At least one provider cited the importance of involving the patient in the decision-making process, citing that doing so makes the patient more comfortable.

Most of the time, especially when prescribing something or...talking about the screenings, we'll talk about it, tell the patient all about it, but ask them, do they want to participate, do they want to take this medication, do they want to have this screening, and try to get some feedback from the patient so that it is a shared decision and it's not like we're just telling them, "You have to do this," or "You need to do this." We like them to feel comfortable with the decision.

Assessing Patients for Health Literacy

Each of the rural healthcare providers was asked if their patients' health literacy was assessed in the clinical setting. The majority of the participants, 92% (11/12), stated that they did not have an official method to assess health literacy in their practice.

Several rural providers shared their concern that they had patients in their practice who they believed could not read based on their observations.

No. Not standard, and I think they need to be... and they may not be able to read at a certain grade level. It's been interesting. The way I usually discover it is with medication issues. And one of the biggest... I had a guy, even after we discovered that he had literacy problems, he would still use the same cover-up that he always did, even though he knew I knew there was a problem. His excuse was, "Oh I can't read that print," and he would always hand it to his son, who was in his 20s. He'd say, "Read that for me." And we discovered after a while that he couldn't read anything, no matter how big the print was.

A lot of times what I do, because I do like to go over their lab results with them, or I'll—a lot of times I'll know because they'll say, "I forgot my reading glasses. You know, I don't have my glasses," and in that instance, I know they can't necessarily read. Or if I'm going over their lab results with them, I usually sit next to them and hold the sheet in front of them, and a lot of times they're not following me.

Of the rural providers who did assess the patient's health literacy, 50% (6/12) said they used some informal methods like asking patients about their ability to read, having the patient read a pamphlet, or completing paperwork.

"We will...you know, ask them. You know, we'll give them something, ask them can they read and stuff like that".

Based off their particular disease process, I pick that pamphlet and I have them read a section of it for me so they have an understanding of things they need to do at home. If they can't get through that, then I know what we're dealing with: we're dealing with the literacy.

"Not in any type of formal way, but they have to fill out a paper to let us know, you know, basic information, insurance information, addresses, social security numbers and whatever".

Tools Used to Assess Patients' Health Literacy

Each of the healthcare rural providers was asked about tools used in the clinic to assess their patient's health literacy. Of the rural healthcare providers interviewed, 100% (12/12) did not have access to or use a formal health literacy assessment tool. Many cited using their judgment, instead, to determine patients' literacy levels.

“No, we don’t have any official tool or anything. I don’t even think there’s a questionnaire about grade level”. “No type of tools”. “We don’t do a formal literacy test. It’s just a matter of us knowing”.

It’s an embarrassing thing for adults, and so it’s not something that I have yet learned how to just say, “Oh, do you know how to read? You don’t [know] how to read?” You know? And so, what I do is I do take a mental note of those patients where I know or I think that they can’t read.

Multiple rural providers reported being concerned that patients do not admit when they don’t understand the medical information presented to them.

“Quite often, they don’t let you know that they do not understand. Because a lot of them will sit there and shake their head yes and whatever”.

I get a lot of [patients] who will tell me, after they’ve been to the emergency room two or three times, that they didn’t understand that doctor that they saw the last couple of times, and they did not interrupt them and tell them, “I don’t understand you,” or “Will you repeat this?” or “What are you talking about?” And I know that sometimes they’ll leave and you know they don’t understand because they’ll come back and they’ll be taking their medications the wrong way or not taking ‘em at all.

Support for Health Literacy

The participating rural providers offered a varied approach for handling patients who appeared overwhelmed or those who did not understand the health information provided to them. There were some common themes among the group responses, including that 4/12 (33.3%) of participants stated that they attempt to simplify the information to encourage patient understanding, 3/12 (25%) of participants reported allowing additional time with patients to ensure

that they understand the information given to them, 2/12 (16.7%) of participants said they repeat information to patients to facilitate understanding, and 2/12 (16.7%) of participants mentioned ensuring patients have family members or support systems present who can help them understand the information presented to them.

Participating providers commented on the importance of simplifying information so that patients can participate in the conversation and understand diagnoses, treatment options, and plans. The providers seemed to understand that patients have varying levels of education and health literacy that can affect how they perceive and interpret information presented to them.

Really, every patient that you got, you need to get on their educational level in order to explain things to them. I try very hard to break it down in such a manner that I think they will [understand]. And it's very interesting to me, too, because, you know, sometimes it gets to be a different language.

Providers also stated the importance of spending more time with patients who may not understand the information presented to them. This extra time taken to connect with patients seemed to be an important step to ensuring information was appropriately relayed to patients. "We take as much time as we need to make sure they understand before they leave".

Some participating providers reported that they often repeat information to patients to ensure that they fully understand it. One provider reported going a step further and writing down information for patients.

I will start over, I will face them, and I will ask what did they understand out of the conversation, and I'll let them take their time, and then I'll repeat it. If I still feel like they're not understanding it, I will write it down for them, you know, number one, number two, number three.

Few participating providers reported that they sought the support of family members to help patients understand the information presented to them.

If they don't understand, we try to contact the family so that he or she can understand a little bit better. [We make] sure that they have a support system or somebody that's going to help them in regard to like their medications, appointments, that sort of thing.

Healthcare Providers as Authoritative Figures

Some rural healthcare providers report that they are seen by patients as authoritative figures and patients tend to agree with what is said to or asked of them (Coombs et al., 2022). Most of the participating rural providers agreed with this statement and realize that this can distort the conversation, perhaps preventing patients from being active participants in their care, asking for clarification, or objecting to plans set forth by the provider. Of the respondents that answered this question, 87.5% (7/8) indicated that they are seen as authority figures in their community, 37.5% (3/8) of respondents indicated that this authority was built on trust, and 25% (2/8) indicated that this authority figure persona stems from historical cultural factors.

Discussion

The findings from this research suggest that healthcare providers in predominantly rural Alabama care for patients with limited health literacy, that providers attempt to compensate by taking time and providing written information, and that providers do not use formal health literacy assessments. A majority of the patients seen by providers were rural African American. Obesity, diabetes, and hypertension were this population's most commonly cited medical conditions. These conditions are associated with a metabolic syndrome (Bradley et al., 2007; Samson & Garber, 2014). The high prevalence of these chronic conditions mirror that of the many African Americans living in the US and is a determinant of increased morbidity and mortality in this population

(Musemwa & Gadegbeku, 2017; Spears et al., 2018). Given the predominant healthcare disparities seen in the African American population, particularly related to chronic disease, it is important to review the role of health literacy in this population with the goal of empowering patients to be active participants in their health and well-being. The patients involved in shared decision-making have better health outcomes, better healthcare experiences, and likely lower costs (Stacey et al., 2017). Rural healthcare providers should engage in shared decision-making with their patients to achieve the best outcomes, but not all practitioners employ this method (Coulter & Collins, 2011). Many of the participants in this study stated that they attempted to include their patients in the decision-making process, even though they also realized that patients' literacy was a barrier to understanding the information presented to them. In a study on decision-making, Coulter and Collins cite low levels of health literacy as one of the reasons why shared decision-making is not the norm in medical practices. Shared decision-making interventions have been evaluated with patients presumed to have lower health literacy and appear beneficial to disadvantaged groups with lower literacy or lower socioeconomic status (Stacey et al., 2017; Shah et al., 2010).

Many providers in this study reported not having a formal method of assessing patients' health literacy status. Instead, most used their judgment or surrogate methods (e.g., reading office brochures) to determine patients' ability to perceive the information presented to them and to use that information to manage their health. There are, in fact, several tools to address health literacy and their administration time can take as little as 1-2 minutes. However, these tools are mainly used in research instead of in actual practice (Hersh et al., 2015; Stacey et al., 2017; Coulter & Collins, 2011). Given the time constraints primary care providers face, perhaps the use of simple tools developed for primary care, such as the Newest Vital Sign (Shah et al., 2010; Weiss et al., 2005). would prove beneficial. Although most healthcare provider participants in this study

believed their patients had a lower literacy level, studies show that healthcare practitioners generally overestimate their patients' literacy (Jukkala et al., 2009; Kelly & Haidet, 2007). This discordance in estimating patients' literacy levels may be a source of disparities and result in poorer health outcomes for people of color (Kelly & Haidet, 2007).

There is a need for healthcare providers to better recognize and respond to health literacy problems in the clinical setting. As evidenced by the providers in this study, patients do not always volunteer information related to their literacy or ability to comprehend information presented to them. This hesitancy to share their literacy status may also drive patients to seek other sources of information that do not require them to disclose their literacy inadequacies. Traditionally, healthcare providers have been a trusted source of health information, but recent research shows that people with lower health literacy were less likely to trust their physicians and more likely to use television, social media, blogs, or celebrity webpages for health information. (Coronado-Vázquez et al., 2020; Liu et al., 2018; Chen et al., 2018; Gupta et al., 2014; Paasche-Orlow & Wolf, 2007). identified health care advocates, which were primarily women family members, as a source of information.

Limitations

Limitations of this study included inaudible speech in the qualitative interviews that could not be distinguished for transcription or by the researchers. These occurrences were few and did not diminish the overall content of the data collected. While we believe that the participating providers adequately responded to the questions asked, their responses are specific to providers working with predominately rural patients in Alabama. Additionally, providers based in Tuscaloosa County technically do not operate in a fully rural area; however, many of the patients seen by Tuscaloosa County providers are indeed rural and they travel to Tuscaloosa for primary

care. Future research studies could explore a larger sample from a broader region to determine if the results are similar to those found in this study.

Conclusion

Rural populations are at higher risk for negative health outcomes as compared to their urban counterparts (Spears et al., 2018). Leveraging an understanding of literacy results in improved outcomes in physician-patient interaction (Stacey et al., 2017). Improved understanding of patients' health literacy enables providers to tailor treatment plans to the individual patient and enables patients to have a more comprehensive understanding of their care plan (Coulter & Collins, 2011). By becoming more aware of the health literacy levels among their patient population, rural healthcare providers can provide better care and improve overall patient outcomes.

Through a better understanding of patient's health literacy needs and working to improve health literacy in rural communities, providers can help to reduce the cost of healthcare in these rural communities. In rural health communities, there are more patients per physician as compared to their urban counterparts (Coronado-Vázquez et al., 2020). Additionally, individuals in rural communities visit their physicians more often than their urban counterparts (Coronado-Vázquez et al., 2020). All of this results in a greater strain on the healthcare system. In the study, participating rural providers also reported patients having difficulty following care plans due to a lack of understanding and having to take extra time to explain the patient's results and medication. This delays the process of a patient getting the care he or she needs. With improved health literacy, patients report fewer doctor visits than those patients with worse health literacy (Liu et al., 2018). Through improving health literacy, the strain on the healthcare system could be reduced.

The authors believe that there is a great need for healthcare rural providers to understand the components of health literacy, to have a simple and uniform way of assessing health literacy status

and employ tools to address health illiteracy including the use of social support networks. Only by doing so can rural providers truly have shared decision-making with their patients and ensure the best health outcomes.

Conflicts of Interest

These authors declare no conflicts of interest.

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