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Health literacy and asthma management among African-American adults: an interpretative phenomenological analysisCourtnee Melton, PhD, MS¹, Carolyn Graff, PhD², Gretchen Norling Holmes, PhD³, Lawrence Brown, PharmD, PhD⁴, and Jim Bailey, MD, MPH⁵¹Research Center on Health Disparities, Equity, and the Exposome, University of Tennessee Health Science Center, Memphis, TN, USA, ²College of Nursing, University of Tennessee Health Science Center, Memphis, TN, USA, ³Center of Excellence in Rural Health, College of Medicine, University of Kentucky, Lexington, KY, USA, ⁴School of Pharmacy, Chapman University, Orange, CA, USA, and ⁵College of Medicine, University of Tennessee Health Science Center, Memphis, TN, USA**Abstract**

Objective: African-Americans share a disproportionate burden of asthma and low health literacy and have higher asthma morbidity and mortality. Factors that link the relationship between health literacy and health outcomes are unclear. This study aimed to use patients' experiences of managing asthma to better understand the relationship between health literacy and health outcomes. **Methods:** This study was the qualitative component of a mixed methods study. Following quantitative data collection, four participants, two with low print-related health literacy and two with adequate print-related health literacy, completed semi-structured interviews. Interview data were analyzed using interpretative phenomenological analysis. **Results:** Three themes emerged from the analysis: information desired versus information received, trial and error, and expectations of the patient–provider relationship. Individuals with adequate print-related health literacy had different strategies for overcoming barriers related to communicating with their providers, learning about their disease and experiences of discrimination within the healthcare system. **Conclusions:** Individuals with adequate print-related health literacy may be more equipped to participate in shared decision making and feel more confident to successfully manage their disease. It is also important that health literacy is discussed in the context of the cultural and racial background of the population of interest. This interdependent relationship between health literacy and culture is particularly important for African-Americans.

Keywords

Culture, health disparities, minority health, patient–provider communication

History

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Introduction

Asthma affects 24.6 million people in the United States, is responsible for 14.2 million days of missed work [1], and costs \$30 billion dollars in direct expenses annually [2]. While asthma affects all races, African-Americans share a disproportionate burden of the disease. In addition to a higher prevalence of asthma, African-Americans have higher asthma hospitalization rates and higher asthma-specific mortality rates [1,3]. These disparities result in more days missed from school and work for African-Americans [4], and while there are a variety of factors that contribute to these disparities, health literacy may be a key factor as it influences how individuals interact with the healthcare system and particularly, patient–provider communication.

The Institute of Medicine defines health literacy as “the degree to which individuals have the capacity to obtain,

process, and understand basic health information and services needed to make appropriate health decisions” [5]. In addition to increased asthma morbidity and mortality, African-Americans are also more likely to have low health literacy. Disparities in health literacy are not necessarily due to race, but to differences in education, culture and the healthcare system.

Research suggests that individuals with higher educational attainment are less likely to have low health literacy [5]. Given that African-Americans tend to have lower levels of educational attainment overall, compared to non-Hispanic Whites [6], lower health literacy rates tend to be more prevalent as well, with 58% of African-American adults compared to 28% of White adults having low health literacy [5].

Culture, an integral part of health literacy, influences how people define health and illness. It also influences health behaviors, perception of medical treatments and how symptoms are described [7,8]. Culture is defined as “the integrated pattern of human behavior that includes thoughts, communications, actions, customs, beliefs, values, and institutions of a racial, ethnic, religious, or social group” [9]. African-Americans have cultural beliefs and attitudes that influence

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how they manage asthma and how they interact with the healthcare system.

Hardie et al. [10] examined ethnic differences in words used to describe breathlessness and found that African-Americans used different words compared to Whites. African-Americans were more likely to report upper respiratory symptoms (i.e. tight throat, voice tight and itchy throat), whereas Whites were more likely to report lower respiratory symptoms (out of air, aware of breathing and hurts to breath). Phrases such as “itchy and tight throat” are not commonly used to describe asthma symptoms. Trochtenberg and BeLue [11] also explored descriptors of dyspnea in African-Americans and found that participants had difficulty recognizing their own wheezing and used their rescue inhalers when they “just didn’t feel normal.” African-Americans’ use of less common symptom descriptors and health providers’ reliance on these self-reported symptoms may result in improper diagnosis or inadequate treatment.

Regarding health beliefs, Apter et al. [12] found that African-Americans had greater fear of taking ICS and less knowledge about asthma compared to other groups. Le et al. [13] also examined African-Americans beliefs about ICS. They found that African-Americans were more likely to have negative beliefs about asthma medications such as not believing that they required as much medication as their physician prescribed or that regular use of medications would decrease their tolerance to the medications. Cultural differences in how asthma symptoms are described and health beliefs among African-Americans influence how patients interact with healthcare providers; these differences can influence patients’ health literacy.

Healthcare interactions take place within a larger society. Societal norms and realities in the larger society are present in health care, as well. Both patients and providers bring their attitudes, experiences and culture into patient–provider communication. African-Americans have historically experienced injustices by the medical community [14–17], and these past injustices have created a distrust of the healthcare system. It has also been documented that African-Americans receive lower quality of care compared to Whites [18], and African-Americans also believe that they receive lower quality care and are treated differently than Whites [19]. For example, physicians perceive African-Americans and individuals with low socioeconomic status (SES) less favorably than Whites and high SES individuals [20]. African-American patients have more negative attitudes toward health care, view physicians more negatively and are more likely to perceive racial discrimination when interacting with the healthcare system [20]. Minority patients are also less likely to receive empathy from physicians, establish rapport, receive adequate medical information and be encouraged to participate in the decision making process [21]. Previous research has demonstrated that education, culture and different experiences in the healthcare system contribute to low health literacy among African-Americans.

Low health literacy is associated with decreased asthma knowledge [22], decreased self-efficacy [23], decreased willingness to participate in the decision making process [24] and an increased number of asthma-related

hospitalizations and emergency department visits [25,26]. Furthermore, African-American patients exhibit greater difficulty communicating with providers compared to Whites. They are less likely to engage in shared decision making, have greater distrust of the healthcare system and are more passive during medical encounters [27,28]. Understandably, patient–provider communication is a partnership. Both parties contribute to the effectiveness of the interaction, and adequate communication skills are needed. Patients must be able to ask questions, accurately describe their symptoms and recount their medical history [27]. Physicians and other healthcare providers must be able to describe illness and treatments in plain language, develop rapport with the patient and be willing to listen and negotiate. Communication is most successful when both parties have the aforementioned skills. The patient also has the ability to influence how the physician communicates. Physicians respond positively to patients who actively participate in the interaction. If a patient gives details about their symptoms, concerns, medical history and asks questions, the physician is more likely to treat the patient as partner in the decision-making process [28]. Qualitative analysis of patient–provider interactions found that compared to individuals with adequate health literacy, patients with low health literacy were more likely to ask questions for clarity purposes as opposed to asking questions that resulted in more in-depth conversations [29]. Similarly, Arthur et al. [30] found that compared to patients with adequate health literacy, patients with low health literacy had more paternalistic interactions with their physicians. These interactions were characterized by the physician dominating the discussion and the patient being more passive. Decreased involvement in interactions among patients with low health literacy is concerning as research has found that patients with low health literacy benefit more (i.e. greater self-efficacy) from active participation with physicians than patients with higher levels of health literacy [31]. When rating patient–provider interactions, patients with low health literacy reported feeling more confused about their care because their providers did not explain things well and that they did not have enough time to explain their concerns to their providers when compared to patients with adequate health literacy [32]. Differences in patient–provider communication among individuals with low health literacy negatively impacts their ability to manage their disease. Health literacy’s contribution to patient–provider communication is important because effective communication is associated with more patient satisfaction, increased adherence to treatment and better health outcomes [21].

The National Institute of Health recommends that all individuals with asthma receive asthma action plans and continuous asthma self-management education from diagnosis through follow-up care [33]. Although evidence-based guidelines for asthma education exist, there has been a low adoption of these recommendations. Furthermore, the dissemination of standardized asthma-self-management education may be more difficult in low-income, minority populations who experience greater difficulties communicating with providers due to low health literacy and the lack of culturally appropriate education materials. These factors may also contribute to asthma disparities seen among African-Americans [34].

Compared to other chronic diseases such as diabetes, there is limited research on the prevalence of low health literacy among African-Americans with asthma, especially regarding the degree to which low health literacy contributes to poor health outcomes [3] and the patient experience of managing asthma with low health literacy. Yet, it is vital that the perspective of this population is included in research to gain better understanding and to ultimately inform clinical practice and decrease disparities. The majority of chronic disease management takes place outside of health providers' care. Individuals make daily decisions about their health and are indeed experts about their disease. Therefore, efforts to improve patient outcomes should include the patient perspective of disease management, presented in this study.

Methods

This data was collected as part of a larger mixed methods study that examined mediators of the relationship between health literacy and health outcomes among African-American adults with asthma. The mixed methods study was a sub study of a multi-site clinical trial testing the effectiveness of two different types of asthma medications in African-American adults with asthma. The inclusion criteria for the clinical trial required that all participants must have been previously diagnosed with only asthma and no other respiratory diseases, and this diagnosis was verified by their medical records. In addition to the diagnosis, participants also had to have a lifetime smoking history of less than 10 pack years. This study, the qualitative portion of the mixed methods study was exploratory in nature, focused on the patient experience and illuminated different topic areas related to health literacy (i.e. information seeking behaviors, patient-provider communication and self-management behaviors). Prior to completing the interviews, participants completed cross-sectional surveys. Survey data collected included demographic information, numeracy [35], print-related health literacy [36], self-efficacy [37], asthma knowledge [38], asthma control [39] and asthma-related quality of life [40]. Health-related numeracy was determined using the Newest Vital Sign (NVS). While the NVS does not measure numeracy alone, it is more numeracy oriented than other health literacy measurement tools. Previous studies have also used the NVS as a measure of health-related numeracy [41–43]. The NVS scores were dichotomized into either adequate or possibility of limited numeracy. Scores ranging from zero to three were classified as possibility of limited numeracy, and scores between four and six were classified as adequate. Print-related health literacy was measured using a test developed by Chew et al. [36]. The participants were asked, "How confident are you filling out medical forms by yourself?" They responded with "extremely", "quite a bit", "somewhat", "a little bit", or "not at all." Based on previous literature [36,44], the "somewhat" response was used as the threshold. Participants who answered "somewhat", "a little bit" or "not at all" were classified as having low print-related health literacy, and those who answered "extremely" or "quite a bit" were classified as having adequate

print-related health literacy. Following the quantitative phase of the larger study, a list of participants with adequate print-related literacy and a list of participants with low print-related health literacy were generated. Participants from each list were then called to see if they would be willing to complete and interview. The first participants who agreed to participate and had transportation to come to the office to complete the interviews were selected, and two participants with low print-related health literacy and two participants with adequate print-related health literacy completed semi-structured interviews. Participants received no incentive for completing the interviews.

Interpretative phenomenological analysis (IPA) is a qualitative approach that originated in the field of psychology and is exploratory in nature [45–47]. It is appropriate when trying to understand how an individual perceives and makes sense of a situation [48]. IPA is a combination of phenomenological theory and symbolic interactionism. Phenomenology is concerned with the individual's perception and experience and does not aim for objectivity. Symbolic interactionism is also focused on subjectivity, but believes that the meaning of the individual's experience is interpreted through the researcher. IPA is focused on the individual but embraces the interpretative and analytical role of the researcher [47,48]. Small sample sizes are used when conducting IPA as this type of analysis focuses on developing an in depth understanding of a particular group as opposed to making generalizations [48]. The small sample size of four participants was appropriate for the methodology used in this study.

There are basic guidelines for analyzing data using IPA. The first stage of analysis involves becoming familiar with the data by reading the transcript multiple times. During this stage, the researcher notes anything they find interesting or significant in the participant's responses. The second stage involves turning initial thoughts and comments into emerging themes. These emerging themes are phrases that embody what was found in the initial notes. Next, the researcher looks for connections between the emerging themes, which involve a theoretical or analytical ordering of the emerging themes. These connections must be supported by the respondent's actual words. Finally, the emerging themes are put into clusters, and the clusters are given a name that represents the emergent themes. Again, the clustering is supported by the transcript [48].

Each participant completed one interview, and interviews lasted between 45 and 60 minutes. All interviews were recorded and transcribed verbatim. Following transcription, data were analyzed using the four previously described steps outlined by Smith and Osborn [48]. Each case was analyzed separately and then convergent and divergent themes among cases were examined. Themes found in one interview were not used to inform subsequent interviews. Once all of the cases were analyzed, final superordinate themes from all cases were determined. QDA Miner (Provalis Research, Montreal, Quebec, Canada) was used for data analysis. After initial coding, a second researcher reviewed the transcripts to insure the themes were represented by the data from each participant. This study received approval from the Institutional Review Board at the University of Tennessee Health Science Center.

Table 1. Characteristics of interview participants.

| Participant | Age | Education | Insurance | Print literacy | Numeracy | ASE | Asthma knowledge | AQLQ-S | ACQ | Gender | Smoking history |
|-------------|-----|--------------|-----------|----------------|----------|-----|------------------|--------|------|--------|-----------------|
| 1 | 57 | Some college | Public | Low | Limited | 56 | 67% | 4.59 | 1 | Female | <10 pack years |
| 2 | 64 | High school | Uninsured | Adequate | Limited | 54 | 59% | 5.03 | 1 | Female | <10 pack years |
| 3 | 68 | <High school | Public | Adequate | Limited | 57 | 63% | 5.16 | 1 | Female | <10 pack years |
| 4 | 59 | Some college | Public | Low | Limited | 57 | 71% | 3.16 | 2.83 | Female | <10 pack years |

Print literacy is print-related health literacy. ASE (Asthma Self-efficacy Scale) scores ranged from 14 to 70 with higher scores indicating higher self-efficacy. Asthma knowledge scored as percent correct. AQLQ-S (Standardized Asthma Quality of Life Questionnaire) scores ranged from 1 to 7 with higher scores indicating better quality of life. An ACQ (Asthma Control Questionnaire) score of 0.75 or less indicates an 85% chance that the individual has well-controlled asthma. A score of 1.50 or higher indicates an 88% percent chance that asthma is not well-controlled. All of the participants had been nonsmokers for at least one year prior to being interviewed. A pack year is defined as 20 cigarettes smoked every day for one year.

Results

Sample characteristics of the interviewees are listed in Table 1. Three major themes emerged from the analysis: information desired versus information received, trial and error, and expectations of the patient–provider relationship. Individual clusters and themes for each participant are listed in Table 2.

Information desired versus information received

All participants noted discordance between the content, depth and amount of information that they received from their healthcare providers and the information that they desired to successfully manage their asthma. Participants were given basic information about the pathophysiology of asthma and how to take asthma medications properly. Some participants only received oral information from their providers, while others attended asthma education classes. All participants expressed a desire to learn about their disease and suggested formal educational opportunities to get information. This was demonstrated by Participant 1 who said, “If you got asthma, why not have a class and let people come there and get educated about asthma you know?” Participant 2 stated:

“No they never sent me to an educational class, but that probably would be good for someone like me that has the determination that they decide that ‘I’m not gonna use that pump.’ Ok so a person like me should have already been in a class. It should have been something set out. You need to go to this class and see what happen to people when they don’t use that pump every day.”

Participants also had ideas about the content that these classes should cover. When discussing class content, Participant 2 said:

“What is asthma? What medications that they have on the market for asthma. Uh, what uh triggers. What can trigger asthma? And what you need to do once you realize that you’re having a asthma attack because I’m telling you, a lot of people don’t know they havin’ a asthma attack.”

The need for more information about what triggers one’s asthma was important to all the participants. Participant 1 who had previously attended an asthma education class suggested changes to the content saying, “In 2004, they didn’t really say how serious (asthma was). They let us know

it (asthma) could get serious whereas everybody should know it’s a serious thing . . . I mean people die have died from having asthma attack. It could get that bad.”

In addition to an educational class, participants also had other suggestions to help patients to learn about asthma. Participant 2 said:

“I think it should be a pamphlet in every asthma doctor’s office; that if you goin’ to specialist, they need to have to give you so that you can read up on it . . . and um, I think they need to have in that pamphlet some foods that you need to avoid uh, when you have asthma.”

While all participants had a desire to learn about their asthma and wanted structured opportunities, participants with adequate print-related health literacy were more proactive than participants with low print-related health literacy in obtaining the information that they needed. Both participants with adequate print-related health literacy reported using computers to learn about asthma. Participant 3 said:

“I have become computer literate. So I go down and look on the computer about asthma. And with me having it from 95 up until now, I uh, didn’t really have a source of information unless I got sick . . . but now if there’s something new that I need to know, I keep in touch with what asthma is on the computer.”

Participant 2 said, “When I really learned about asthma, I learned it from going into the computer and pullin’ stuff out.” Although both participants relied heavily on computer information, neither of them knew how to determine if the information was from a reliable source. Participant 2 reported, “If I’m reading something, and it’s some of the side effects I’m having, I believe it. And if it’s not, then I go back and ask my doctor.” When asked how she determined if the information she found on the computer was true, Participant 3 reported:

“Well to tell you the truth, I don’t cause it’s so much going on on the computer. And with me being the age I am, I am thankful that I can go in and put it on the uh on the website, and type in asthma uh asthma related, and they will go to the source.”

Both participants also noted that they take internet information with them to their doctor’s appointment to

Table 2. Individual participant clusters and emerging themes.

| Participant | Cluster 1 | Cluster 2 | Cluster 3 | Cluster 4 |
|----------------|--|---|--|---|
| 1 ^a | <i>Doctor knows best</i> – Expectations of relationship – Growing process – Time and comfort – Impact of comfort/trust | <i>Trial and error</i> – Intentional self-monitoring – Self-consciousness | <i>Information received vs. information received</i> – Provider initiated – Patient preference or initiated | <i>Asthma is in control</i> – Inevitable – Fear and anxiety – Personal experience of helplessness |
| 2 | <i>Doctors as partners</i> – Mistrust – Expectations – Patient responsibility | <i>Trial and error</i> – Self-management as a process – Intentional self-monitoring | <i>Information received. information wanted</i> – Provider initiated – Patient preference or initiated | <i>Patient as an expert/consumer</i> – Ownership of body/disease – Medical care as a service – Development of knowledge base |
| 3 | <i>Doctor as a partner</i> – Patient responsibilities – Influence of culture/race – Expectations of doctor – Partnership development | <i>Trial and error</i> – Asthma is emotional – Self-management as a process | <i>Information as power</i> – Information yields confidence – Information yields better self-management – The more the better | <i>Patient as an expert/consumer</i> – Shops for acceptable care – Ownership/expert of body/disease |
| 4 ^a | <i>Patient as the doctor</i> – Mistrust of doctor – Influence of race/culture – Educated by experience – Process to control | <i>Role of the doctor</i> – Attentive listener – Treats the whole person | <i>Information received vs. information wanted</i> – Provider initiated – Patient preference – “Mad scientist” | |

Clusters are in italics followed by emerging themes.

^aA participant with low health literacy.

continue to discuss what they learn. Participant 2 noted, “Most of the time I bring a paper and say this is what I got off the internet.” Participant 3 said, “The more information you receive or however you receive it. TV, computer, book or whatever you um try to see which one is more helpful to you when you get to your doctor’s office.”

Although individuals with low print-related health literacy did not mention using computers to learn about their asthma, they did try to use whatever information was given to them to learn about their asthma. Participant 4 took it upon herself to read the medication inserts that came with her asthma medications but found the information hard to understand. She said:

“I try to learn by reading what’s inside of the package when I open it. You have to be a mad scientist to really understand. But some of it, I kind of you know, you know, get the idea what they’re saying, you know...look like they writing to the doctor.”

All of the participants believed that knowledge of asthma was important and beneficial for individuals with asthma to manage their disease. It is important to note that none of the patients with adequate print-related health literacy mentioned any difficulties understanding the information they received from their doctors or information they found on the internet. Regardless of print-related health literacy skills, all participants stated that at this point in their life, they had enough information to successfully manage their asthma.

Trial and error

The participants described asthma self-management as a learning process. This theme was best described by Participant 3 who said, “I see that it’s a trial and error which you can’t really afford to have errors.”

Participants had different feelings about being in control of their asthma. Both of the participants with adequate print-related health literacy felt that they were in control of their asthma. However, feeling in control of one’s asthma did not mean that an individual exercised complete control in every situation. This was demonstrated by Participant 2 who said, “Um most of the time, I feel like I’m in control. But when you have that bad asthma attack, no you’re not in control anymore. Asthma can kill you if you don’t manage it right.” Unlike the participants with adequate literacy, participants with low health literacy did not give a definitive yes about being in control of their asthma. Participant 1 said, “I mean I do what I’m supposed to do, and it’s been working pretty good. When it [asthma] wants to cut up, it’s gon’ cut up, and there’s no way I can uh stop it.”

When discussing the relationship between patient and providers, participants reported the expectations they had of their providers. In addition to provider expectations, participants discussed their roles in the relationship and different factors that affect their interactions with their providers.

Expectations of the patient–provider relationship

All participants expected their provider to listen to them and expressed dissatisfaction when they felt that their providers

were not listening to them. Participant 2 reported, “I would just tell him [doctor]; I just want you to listen to me about what’s going on with my body instead of writing while I’m talking to you. Look at me. Then I know that you listening to me.” Participant 4 said, “I didn’t feel like they were really interested. They were just talking. This is what they supposed to do, just talk. It wasn’t really concern.” In addition to being good listeners, participants expected their doctor to treat them as a whole person and not just treat their asthma. Participant 4 reported, “I just want my doctor to recognize who I am...and they say ‘well let’s see how you doin’;’ you know.” Participant 1 reported, “She [participant’s doctor] know pretty much what’s going on with me period. She know with my body.”

Participants also acknowledged that although their providers knew more than they did, but they still had something to contribute and wanted their providers to recognize their contributions. Participant 2 said, “They’re in charge. I do what they say, but we have a good relationship. And I don’t care how long it takes. He knows he has other patients, but I will talk to him.” Participant 1 said, “If they [doctors] don’t agree with me, they’ll listen to me or whatever...they’re going to run some tests to confirm what they think or to rule out what I think.”

Participants with adequate print-related health literacy reported seeking care elsewhere when their expectations were not met. Participant 2 said, “You gonna talk to me or you gonna put me on out, and I’m gonna go find me another doctor.” Standards of acceptable care extended not only to the provider but also to the entire experience. Participant 3 said, “Except the last time I called to make an appointment, and then the receptionist was really awful. Well the heck with that. So I went to another doctor. They were good.” The participants with low print-related health literacy did not report changing doctors because they were not satisfied with the care they were receiving.

As previously discussed, participants want their providers to listen to them. All of the participants reported that they were responsible for telling their providers all of their symptoms. Participant 3 said, “I’m gonna tell them everything.” Participant 2 said, “It is my responsibility to tell the doctor the truth.” Participants with adequate print-related health literacy were more engaged as patients than participants with low health literacy. They believed it was important to bring information to their providers. Participant 2 said, “I think today, they really look for you to go into the computer and come back and say something.” Participant 3 reported:

I know they know more than I do, but I share this information with them. What I have seen, and uh I tell them, “You know she gave me flovent, and she gave me this, and she gave me that, but I find one of them to be very helpful.”

Participants with adequate print-related health literacy also reported taking ownership of their disease and their bodies. Participant 3 said, “I’m tellin’ them what’s going on with me cause I know my body.” Participant 2 said, “It’s my health. It’s not theirs.” These participants also treated

the patient–provider relationship as a partnership. Participant 2 said, “You got to have some uh uh focus on what you want to happen to you with this asthma other than waitin’ on your doctor, takin’ your hand, walkin’ us.” Participants with adequate health literacy also believed that a good relationship with their providers was necessary for taking care of their asthma. Participant 2 reported, “You have to build rapport with your doctor. It come from building.” Participant 3 said, “The best thing to do is to have good communication with your doctor.” These ideas of rapport and bringing information to your doctor’s visits were not reported by individuals with low print-related health literacy. Although participants with low print-related health literacy did not discuss building rapport with their providers, one participant noted the impact of good rapport on her self-management. Participant 1 reported, “I’m comfortable to the point where I don’t have a problem taking my medicines. If I’m not comfortable with my doctor, I’m not going to take the medicine.”

Participants discussed several factors that impacted their relationships with their providers. These factors included mistrust, comfort and race. Participants reported their mistrust of doctors regarding the medications that they were prescribed for their asthma. Participant 1 said, “. . . My actual feeling about doctors are that they are in with the pharmacies . . . and it may not be something that you really need, but they got a contract or whatever.”

In addition to mistrust about providers’ prescribing habits, participants recalled experiences of being an African-American in the healthcare system. Participant 4 reported, “You hear how others they have done people in the past. You know, specially our people, you know. And uh, it make you wary. That’s the reason a lot of Blacks are wary about doctors.” This patient also recalled an experience where she felt the provider did not want to touch her because she was African-American. She reported:

“I have went to the doctor and he say ‘You got asthma?’ Mmhm that’s right. Uh pull that coat and then he got a ink pen and did something like he didn’t want to touch me . . . Maybe it’s a phobia or maybe you don’t like brown skin mmhm.”

Another participant also had negative experiences with providers. Participant 3 reported, “I think when I first got pregnant and went to the doctor I was really timid . . . you still had some of these prejudice white folks.” It is important to note that the participant whispered when she said “white folks” and would often touch and point to her skin instead of saying “black.”

The topic of race was not introduced by the interviewer. The influence of race evolved from discussing patient–provider communication. In addition to race, a participant also felt discriminated against for being overweight, and she felt that providers have looked at her like she was “just disgusting” and attributed her asthma to her being overweight. Participant 4 reported that discrimination is not always overt saying, “Yeah, yeah, suppose to it’s a lot of things they do behind closed doors, and what nobody there to

witness, you know. You know, they say I never done that. I never said that, but you know deep down inside.”

Both participants with adequate print-related health literacy discussed ways to overcome mistrust and discrimination. Participant 2 emphasized the importance of building rapport with her doctor saying:

“You shouldn’t just have to build a rapport. It should be one when you get there, but in this society people look at the way you dress, your mannerisms. They look at your hair. They look at your eyes. They look at your everything, and that’s what they judge you by. They look at you don’t have no money. They look at your insurance. They look at everything. So you have to build rapport with your doctor.”

Participant 3 used information to combat negative experiences saying:

“All you wanna do is learn how to take care of yourself without asking anyone to help and I got to the point where I was real smart . . . so I just started to researching a lot of stuff and that built up my confidence . . .”

Discussion

Interviews revealed that all participants, regardless of print-related health literacy skills, reported a disparity between the information that they received from their providers and the information that they felt was important for them to take care of their asthma. However, participants with adequate print-related health literacy were more likely to supplement the information they received from their providers with other sources of information. This was evidenced by their reports of using the internet and books to learn about their asthma. Because individuals with adequate print-related health literacy were seemingly more proactive about acquiring information about their disease, they may have greater disease knowledge or be more confident about taking care of their asthma. These findings may offer insight into the results of Osborn et al. [49] who found that knowledge, not health literacy, was a significant predictor of self-efficacy. A participant in this study reported that the more information she learned about her asthma, the more confident she felt taking care of her asthma. In addition to seeking more information from outside sources, participants with adequate print-related health literacy were also more active patients. They felt it was their responsibility to bring information from the internet to their doctors. Katz et al. [29] found that patients with low health literacy were less likely to ask questions and participate during a medical counter. A previous qualitative study by Baker et al. [50] found that patients with low health literacy felt that their providers did not listen to them or explain medical problems in a way that they could understand, but these patients were less likely to ask questions or admit that they did not understand. Increased information seeking by patients with adequate print-related health literacy may give patients more confidence, willingness and tools to interact with their providers. In addition to increased information seeking, participants

with adequate print-related health literacy mentioned that they shared responsibility for building rapport with their doctors. Building rapport has traditionally been a responsibility of the provider; however, individuals with adequate print-related health literacy may feel more confident or empowered to build the relationship. Previous research has found that individuals with adequate health literacy were more likely to contribute equally during patient–provider interactions compared to individuals with low health literacy [30]. Although this study and previous research found a relationship between patient activation and print-related health literacy [29,50], other research has reported no association between the two [51]; rather that health literacy and patient activation were associated with different aspects of disease management. Health literacy influenced decision making, while patient activation influenced self-management behaviors. In our study, health literacy influenced both decision making and self-management behaviors. Participants with adequate print-related health literacy worked to build rapport with their doctors, sought health information from multiple sources and shopped for care that met their standards. Participants with adequate print-related health literacy also navigated the healthcare system as consumers. They reported finding new doctors and/or clinics when they were not satisfied with the care their doctor provided or the temperament of the staff who worked at the clinic. Although participants with adequate print-related health literacy were more active, all participants had similar expectations from their providers. In addition to being treated for asthma, the participants desired to be respected, listened to and desired a holistic approach to managing their asthma. Participants with adequate print-related health literacy may be more empowered to make sure they receive the type of care that they desire. It is necessary to help individuals with low health literacy be informed consumers as well.

While participants with adequate print-related health literacy sought more information from outside sources, they did not demonstrate increased asthma knowledge compared to the participants with low print-related health literacy. This finding may appear counterintuitive. However, having low print-related health literacy does not equate to the inability to learn about one's disease. Furthermore, print-related health literacy is only one dimension of health literacy, and the participants differed in their information seeking behaviors, communication with providers and how they navigated the healthcare system. Health literacy is more than the ability to read and comprehend written information and includes the aforementioned skills.

Participants also reported general mistrust of providers and concerns about being treated differently by providers because they were African-American. Both of these factors negatively influenced the patient–provider relationship. These findings support previous research showing that African-Americans have greater distrust of the healthcare system [28]. In this study, perceptions of racial discrimination were based on historical knowledge of racism and personal experiences of perceived racism in health care. Participants were less likely to take their asthma medications as prescribed if they did not trust their provider. This finding supports

previous research demonstrating that poor patient–provider communication has a negative impact on medication adherence [52,53]. Adequate patient–provider communication is important for all patients, but may be particularly important for patients with low health literacy. Providers should carefully listen to minority patients, elicit their concerns and work to build rapport and open communication that leads to a true patient–provider partnership.

In this study, participants recalled perceived discrimination inside and outside of the healthcare system. Participants' introduction of race into their descriptions of patient–provider communication supports the interrelationships between historical perspectives and patient management of asthma. Experiences of perceived discrimination negatively influenced how all participants interacted with their healthcare providers, yet participants with adequate print-related health literacy used strategies such as actively building rapport with their doctors and learning about their disease to overcome their mistrust of doctors and negative experiences due to race. However, participants with low print-related health literacy did not report any of these strategies. Consequently, cultural factors (i.e. symptom descriptors, distrust and negative health beliefs) may exacerbate or contribute to low health literacy by negatively influencing patient–provider communication. Both parties are influenced by the communication style of the other, and both patients and providers contribute to the success of the interaction. If a patient has previous experiences or knowledge of racial discrimination in the healthcare system, they are less trusting of the provider, information they receive from the provider and may be less willing to engage with their provider. A lack of contribution by the patient can result poorer patient–provider communication. Results of this study suggest that individuals with adequate print-related health literacy may have more success overcoming negative experiences and have higher quality patient–provider communication.

Conclusions/key findings

Findings from this study suggest that health literacy influences patient engagement in patient–provider communication and patient activation. Individuals with adequate print-related health literacy place greater importance on their contribution to forming a partnership with their doctors and are more confident and willing to participate in shared decision making and navigate the healthcare system. Although all participants described mistrust of healthcare providers, individuals with adequate health literacy may be more equipped to overcome mistrust of providers. The interplay between culture and health literacy was also important for this population. Future research should examine the role of patient activation and determine ways to empower patients to mitigate the impact of low health literacy as well as interventions that increase providers' awareness and ability to communicate with patients who have low health literacy. In addition to patient activation, the relationship between health literacy and culture should be explored as well. This relationship may be particularly important for minorities and other underserved or marginalized groups. The patient perspective is not only important for identifying and describing issues, but this perspective is

vital to developing solutions to mitigate the impact of low health literacy on health outcomes.

The results of this study have implications for improving patient–provider communication among minority populations. First, providers and healthcare workers should receive training that integrates cultural competency and health literacy. Literacy and communication interventions and cultural competence interventions are not delivered simultaneously, and each of those trainings emphasizes different skills. In this study population, an ideal training would not only review recommended communication strategies (i.e. using non written materials; talking slower; limiting the amount of background information and focusing on specific things patient needs to know for self-care, including family members and other caregivers; and demonstrating skills to patient and having the patient demonstrate the skill to confirm that patient understands) [54] but also take into account the different symptom descriptors, health beliefs and distrust of the healthcare system that is seen among African-Americans. Through the integration of cultural competency and health literacy training, providers would be able to more effectively communicate with their patients and provide care that is patient-centered. Because communication is a dyad, interventions that focus on patient empowerment would also help improve patient–provider communication. Interventions that focus on empowering patients to be involved in the decision-making process can increase patient self-efficacy, assertiveness and shared decision making [55] leading to a more effective and satisfying provider–patient interaction. Effective patient–provider communication is essential to better health outcomes in this vulnerable population. Patient–provider communication can best be improved with both patient and provider focused interventions. Both parties are influenced by the communication style of the other, and both patients and providers contribute to the success of the interaction.

Limitations

This study does have several limitations primarily due to the sample used for the study and that participants only completed one interview. The sample was a homogenous and unique group of older African-American women. While the results may not be generalizable to a wider audience, this sample was useful for achieving the purpose of transferability. The study was not undertaken with the goal of generalizing the findings, but of gaining and in-depth understanding of patients' experiences. IPA is carried out with the belief that an individual's experience and perception can provide insight into a larger phenomenon. We believe these results are transferable to other African-American women with asthma as some of themes found in the interviews were consistent with previous literature. In addition to the homogenous group of participants, only print-related health literacy skill was used to identify participants for interviews. Consequently, all of the participants who completed interviews had limited numeracy skills. The perspective of individuals with both adequate print-related health literacy and adequate numeracy was not included in this study. Exclusion of these individuals may have resulted in decreased insight into the impact of adequate

numeracy. In addition to the homogenous sample, the instruments used to measure health literacy in this study presented limitations as well. The shortcomings of existing health literacy measurement tools have been well documented [56,57]. More research is needed to develop health literacy tools that more effectively and comprehensively measure the concept of health literacy. Although they may not be ideal, the Chew items, like other health literacy measurement instruments, continue to be used to detect inadequate health literacy, particularly in the absence of better measurement tools. Individuals who agreed to participate in the larger study may be different from individuals who chose not to participate. Individuals interested in participating in research may be more active participants in their health care and be more informed patients than those who chose not to participate. In addition to sampling, participants in this study only completed one interview. It is possible that multiple interviews would have provided greater insight into asthma self-management than one interview alone. Finally, this study focused on the patient perspective and did not include the experience of providers. We note that this is a limitation of the study because communication requires both patients and providers.

Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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Interview guide

Introduction: the purpose of this meeting with you is for you to share your thoughts, ideas and feelings about asthma and how you learn about asthma. Furthermore, I want to find out how you take care of your asthma and how you talk with your doctor about your asthma. There is no right or wrong answer to the questions I will ask you. Please stop and ask me a question at any time.

1. I will begin by asking you to think about how you have learned about asthma. How did you first learn about asthma?
2. How do you learn about asthma now?
3. What type of information do you need to take care of your asthma?
4. Where is the best place to get information about asthma?
5. Do you have enough information to take care of your asthma?
6. Do you have the right information to take care of your asthma?
7. What helps you take care of your asthma?
8. What are some things that make it difficult for you to take care of your asthma?
9. Do you feel you have control of your asthma? What makes you feel this way?
10. Do you feel that your asthma is out of your control? What makes you feel this way?
11. What do you feel controls your asthma? You or someone else?
12. How do you feel talking with your doctor about your asthma?
13. What does your doctor do to help you take care of your asthma?
14. Is there something else you think that your doctor could do to help you take care of your asthma?
15. Do you think that your doctor works with you to help take care of your asthma?
16. What should your doctor and other health providers be doing to help you with your asthma?
17. What suggestions do you have for other patients who have asthma to help them take care of themselves?
18. What suggestions do you have for other patients who have asthma to help them work with their doctor?