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Perceptions of Chronic Disease Among Older African Americans: A Qualitative Analysis

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ABSTRACT

Research has documented that African Americans suffer disproportionately from chronic diseases when compared to the general population. Yet, limited research examines older African Americans' perceptions about having chronic diseases. Accordingly, the first aim of the study provided insight into this disparity with the intent of revealing how older African Americans feel about their overall health, and how much they understand about their individual chronic disease(s). The second aim was to gather information about strategies and coping mechanisms older African Americans use to manage their chronic diseases. The purpose of this aim was to determine if any of the strategies they employed were related to positive health outcomes. Two focus groups were conducted with African American older adults who live in community settings. The results from the focus groups indicate that older African Americans are aware of the conditions they have and have developed strong coping methods to help them manage. Recommendations are provided for future research studies and chronic disease management programs.

Keywords: Coping Behavior, Disease Management, Aging, African American, Perceptions

INTRODUCTION

Numerous studies have shown that African Americans disproportionately suffer from chronic diseases when compared to their white counterparts (Debnam et al., 2011; Pleis & Lethbridge-Cejku, 2007). There is, unfortunately, limited information regarding perceptions about such chronic diseases among older African Americans. For example, African Americans with Alzheimer's disease indicate a lower perceived threat of the disorder (Roberts, Connell, Cisewski, Hips, Demissie, & Green, 2003). Higher perceived risk and young age have been associated with higher levels of cancer worry among African Americans (Rees et al., 2004). In addition, chronic disease control is important to older African Americans (Viswanathan & Lambert, 2005), and they tend to be aware of the consequences of not controlling their chronic

diseases (Longtin, Sax, Leape, Sheridan, Donaldson, & Pittet, 2010). Such perceptions about chronic illnesses and diseases are important because they may give us insights into adherence to medical treatment.

Several studies have reported patients' adherence to recommendations for managing their chronic disease were shaped by their health perceptions (Leventhal et al, 1992; McAndrew et al., 2008; Russell et al., 2010). Russell and colleagues (2010) examined variables associated with perceived diabetes control compared with an objective measure of glucose control (A1C) among 334 individuals from a low-income, urban, minority community in East Harlem. Among this predominately female (78%) sample that was nearly half African American (42%), the primary finding was that subjective cues (e.g., perceived adherence to diet, depressive symptoms, and perceived impact of diabetes) were related to perceptions of control, but not actual glucose control. With more research on how accurate perceptions of subjective cues and specific actions affect blood glucose, patients may be able to improve actual diabetes control and modify their daily behaviors (Russell et al., 2010). Findings from Bean et al. (2007) add that those with higher levels of self-efficacy have better self-care. In this study, researchers assessed differences in chronic disease perceptions, self-efficacy, metabolic control, self-care, and retinopathy between 259 Europeans, Pacific Islanders, and South Asians. Granting the study included only three ethnic groups, it provided additional evidence that (1) self-efficacy is a universally important factor in diabetes self-care, and (2) patients with short timeline perceptions either attach very little value to testing or do not understand its chronic nature (Bean et al., 2007).

A number of studies have also linked chronic disease perception among minority patients to self-management. For instance, a cross-sectional survey of 151 type 2 diabetic patients from a large general medicine clinic in New York City focused on determining diabetic patients' knowledge and beliefs about medications that could hinder optimal disease management and the disease itself (Mann et al., 2009). Despite having regular outpatient diabetes care and long-standing disease, the diabetes patients in the study frequently held inconsistent beliefs and unrealistic expectations regarding disease, medication, and treatment (e.g., one-third expected their doctor to cure them of diabetes). Similarly, gaps in participants' understanding and knowledge of diabetes and hypertension was a significant finding in the qualitative study by Russell and colleagues (2010) involving seven community health centers in Boston.

Researchers have noted that in order to address the high prevalence of chronic diseases among older African Americans, it is important to understand the cultural factors that influence the self-care practices of African Americans (Warren-Findlow & Prohaska, 2008). Previous studies have highlighted the importance of family members and friends in their ability to cope with health conditions. African American households are more likely to have large social networks that they use for support (Porter, Ganon, & Armer, 2000). Furthermore, older African American women draw their social support from family members (Warren-Findlow & Prohaska, 2008).

Given the need to examine in greater detail the type of chronic disease perceptions formed by underserved, increased risk populations, Rees and colleagues (2004) call the need for qualitative studies exploring chronic disease perceptions among older African Americans. Thus, to better understand chronic disease self-management among African American older adults who live in community settings, the present study conducted two focus groups at senior centers in Temple and Waco, Texas. These centers provide the seniors with social activities and access to

supportive resources. We chose to conduct our study with the seniors that came to these facilities because they have the independence to regulate their own health behaviors. The first aim of the study was to examine the perception of having chronic diseases. It was expected that this aim would reveal how older African Americans felt about their overall health and how much they understood about their individual chronic disease(s). The second aim was to gather information about strategies and coping mechanisms older African Americans use to manage their chronic diseases. The purpose of this aim was to determine if any of the strategies they employed were related to the positive health outcomes.

Theoretical Framework

This study was guided by the self-regulatory model (SRM) developed by Leventhal (1987). The premise behind this model is that individuals develop cognitive and emotional representations of threats to their health that guide and regulate their individual behaviors (Leventhal et al., 1997; Rees, Fry, Cull, & Sutton, 2004). The model also indicates that both internal and environmental stimuli can influence an individual's cognitive and emotional representation/perception. Internal stimuli may include symptoms of the disease while environmental stimuli may include witnessing a relative's experience with the disease (Rees, Fry, Cull, & Sutton, 2004). Using these representations, individuals develop behaviors to cope with the perceived threat of their chronic disease.

METHODS

Sample

The sample consisted of 17 African American older adults in central Texas, (mean age = 78.7; SD = 12.5; range = 52-100). The majority of respondents were female and widowed. Almost a third (29.4%) attended high school and over 95% of the respondents reported having diabetes and/or hypertension.

Participants were older adults recruited from two different senior community centers; one in Temple, Texas and one in Waco, Texas. Both centers had a large number of African Americans residents (approximately 80%).

Focus Groups

Two focus groups were conducted with previous participants of a chronic illness self-management program as a means to develop new information and new methodologies related to illness perception. All participants provided informed consent. A script was used to ensure coverage of key topics during the focus group. Both focus groups were conducted at the two senior living facilities, in English, and the main study questions were as follows: 1) How do you view having a chronic disease/illness (e.g. diabetes, hypertension)?; 2) Do you think this disease/illness affects how you live your life?; 3) How would your life change if you did not have this disease/illness?; and 4) How do you deal/cope with your disease/illness? Participants were asked not to state their names with their responses to these questions to ensure confidentiality. The participants also completed a brief anonymous demographic exit survey with queries of their age, gender, marital status, race/ethnicity, and any chronic disease(s) that they had. No additional protected health information was collected.

Analysis

Both of the focus group sessions were audio recorded and transcribed verbatim for content analysis. Transcripts were checked for accuracy to ensure that words were recorded

verbatim by the moderator and note-taker. Grounded theory (Strauss & Corbin, 1991) and the SRM framework were used to evaluate the transcripts. The responses were then grouped into the most frequently occurring themes. The themes were developed based on two of the five common SRM representations: 1) illness consequences and 2) illness controllability. NVivo 10 (2012) was used to manage the transcripts and draw connections between themes articulated in the two sessions.

RESULTS

Qualitative data analysis revealed three overarching themes (Table 1) across the two focus groups. Within each of the major themes, a number of sub-themes were also identified. Sub-themes will be discussed within the presentation of each theme.

Table 1: Response Themes

Research Questions	Major Theme	Summary
<ul style="list-style-type: none"> • How do you view having a chronic disease/illness (i.e. diabetes, hypertension)? • Do you think this disease/illness affects how you live your life? • Do you think your life would be different if you did not have this disease/illness? 	Acceptance & Understanding	While the respondents were aware they had an illness, they did not have any concerns or emotions related to it.
<ul style="list-style-type: none"> • Do you have any negative emotions associated with your illness? • How do you feel about your health in general? • Are there any factors about your life that you feel make you feel better overall? 	Religiosity/Spirituality	The majority of the respondents in both groups revealed that their faith or spiritual beliefs enabled them to cope and manage any adverse emotions associated with having a chronic illness.
<ul style="list-style-type: none"> • How do you deal/cope with your disease/illness? 	Social Support	Many of the respondents also indicated that they relied on the support of their families and friends.

Relation to the SRM Framework

Leventhal's SRM framework indicates there are both internal and environmental factors that influence individual perception. The analysis indicated internal stimuli had little to no effects on disease perception. Environmental stimuli indicated that having social support and family had a positive impact on disease perception.

Theme #1: Acceptance & Understanding

One of the initial questions that the focus participants were asked was how they felt about having a chronic illness. While the respondents were aware they had an illness, they generally did not have any major concerns about their condition. One respondent reported that she felt she “takes better care of herself now.” Several respondents reported that they “just feel good.” Another commented that “when you have all these different complaints, just put your trust in God...don’t worry about it because it won’t help you to worry.” Respondents were asked if they had any negative emotions associated with their illness and most people shook their heads or did not have a response.

Thoughts about the disease

One respondent reported that she felt having a chronic disease was a “burden.” She did not like that she was not able to eat what she wanted to eat due to her diabetes.

“I see it as a burden that I have to deal with every day, where I am not able to do what I want, mainly in eating. I am not able to eat what I want to eat because I have diabetes. So every time I fix something to eat it’s in the back of my mind. Should I really eat this or should I really eat this. And how it’s going to affect me later. So I kinda see it as a burden really that I’d rather not have.”

Another woman commented about how having hypertension affected her.

“I have high blood pressure and high cholesterol and I cannot control it. I have tried everything I know, but pills. I refuse to take medicine because I don’t take a lot of medications. And I feel it is a burden also because even though I watch what I eat, I look down and I see my right foot swelling. And if I wear cute shoes, they swell. If I wear tennis shoes they just alright. You can’t dress up in no tennis shoes. And so it is a burden on me, and my lifestyle. It’s the way I wanna go and be. Sometimes I wanna look more like a lady, not like an athlete. And so it’s kinda a burden. I’m doing everything the doctor tells me...Anyway, I try to eat the foods I am supposed to eat. I cut out salt. The only salt content I get is from the processed food. I cook with pepper most of the time. I cook with garlic, onion, all of the herbs that I can get.”

Even among those that felt their respective disease was a burden, they expressed that they were not worried. The reason why most respondents stated that they were not worried stemmed from their faith and social support.

Theme #2: Religiosity/Spirituality

The majority of the respondents in both groups revealed that their faith or spiritual beliefs enabled them to cope and manage any adverse emotions associated with having a chronic illness. Many of the participants’ responses to the questions were related to their spirituality or faith. When a person made a comment about how their faith has helped them, others in the groups would nod approvingly or say “yes.”

Using faith to cope

When asked about how the illness affected their lives, most of the respondents said it did not affect them. Two respondents specifically stated that they were thankful to God that they were still here and that “God has a plan.” One respondent shared how she continues to thank God for the ability to cope with her illness.

“I get up every morning around 6 and check my sugar so I know what can eat during the day. And if it’s low I gotta eat something to bring it up and if it’s too high I have to eat

something to bring it I have been a diabetic since '79. But I'm not taking insulin. And I thank God."

Theme #3: Social Support

Family support

Many of the respondents also indicated that they relied on the support of their families and friends. One lady specifically commented on all the things that her daughter did for her. This included getting her groceries and preparing her food. Another respondent also talked about the challenges she had managing her diabetes but was thankful that her daughter prepares healthy food for her.

Utilizing programs at the center

Several of the respondents also commented about the support they receive from their respective residential community centers. The older adults tend to draw on support from each other. One respondent commented that she has the "center" and that going there "gives her somewhere to go." Another lady with hypertension commented that she participates in exercise through the center and other groups.

"I call it moderate exercise because I do it with the program here through the center. And then I do things otherwise with other groups. I walk in my neighborhood, and I dance. All that kind of stuff."

DISCUSSION

The overall purpose of this study was to understand how older African American adults with chronic diseases think about and perceive their health. The respondents understood that they had chronic illnesses; however, they did not think that the disease had an impact on their overall quality of life. Some felt their illness was just a part of life and overall the respondents maintained positive outlooks. Studies have highlighted the positive effects of maintaining a positive outlook on health can reduce stress and increase overall lifespan (Mayo Clinic, 2017, National Institute of Health, 2015). This information can be instrumental in disease management discussions with older African American patients. Letting these individuals know that maintaining a positive mentality about their health is an important aspect of their overall health care that can lead 1) improved health outcomes and 2) patient participation – an important aspect of disease management (Longtin, Sax, Leape, Sheridan, Donaldson, & Pittet, 2010).

While a relatively small proportion of the respondents commented on the "burden" of the disease, they were aware of what they needed to do to manage it. African Americans tend to have lower levels of compliance with self-management behaviors (Bosworth, Powers, Grubber, Tirpe, Olsen, Orr, & Oddone, 2008; Dickinson & Plauschinat, 2008; Flynn et al., 2013; Shaya, Du, Gbarayor, Frech-Tamas, Lau, & Weir, 2009). Some researchers see medication compliance as the sole responsibility of the patient while others believe that there are several factors that contribute to it (Hu, Juarez, Yeboah, & Castillo, 2014). Based on the responses of the older adults in this particular study, the key factors that appear to be related to managing health conditions are having religious/spiritual beliefs and a support system.

It is well documented that faith and spirituality are closely tied to life satisfaction among older African Americans (Jang, Borenstein, Chiriboga, Phillips, & Mortimer, 2006; Skarupski, Fitchett, Evans, & Mendes de Leon, 2013). Across both of the focus groups, the respondents commented that things were well in their lives because of their beliefs. Even after discussing the

challenges linked to having a chronic illness, they commented on how their faith sustained them. Several studies have noted the effectiveness of working with religious and spiritual leaders to encourage health promotion (DeHaven, Hunter, Wilder, Walton, & Berry, 2004; Rivera-Hernandez, 2015). Health care providers should continue to work with leaders in faith-based organizations to support older adults in manage their chronic illnesses.

Regarding social support, the respondents commented more about the support they gained from being part of their respective community centers. While some remarked on the benefits of the instrumental support they received from their families (Miller & DiMatteo, 2013; Warren-Findlow & Prohaska, 2008), many were managing their conditions by themselves. Several research studies have highlighted the connection between social interactions with older seniors and positive overall health and well-being (National Institute on Aging, 2007). While more research is needed to examine the associations between social interactions and health, going to the community centers appears to be beneficial to their overall health.

CONCLUSION

Limitations

While these findings highlight the unique perspectives older adults have about chronic diseases, several caveats should be considered. First, the demographic data was self-reported. Since this study was designed to establish a baseline understanding about chronic disease perceptions among older African Americans, a limited number of questions were included in the study protocol. These results may not be generalizable to all older adults since all focus group participants were from central Texas. Lastly, the number of focus groups was small, yet Guest and colleagues (2017) suggest more than 80% of themes in qualitative studies are discoverable within two to three focus groups.

Future Directions

This information can be used by health professionals to understand and assist older African Americans with managing their chronic diseases. This information may also be used in tailoring existing chronic disease management programs to ensure they are culturally appropriate. Similar focus groups should be conducted with Hispanic/Latino and Asian older adults. Lastly, more formal qualitative assessments should be constructed to collect more information about perceptions of chronic diseases among older African Americans.

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