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Experiences addressing health-related financial challenges with disease management among African American women with asthma

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Abstract

Objective—Despite economic hardship, compliance with self-management regimens is still evident among individuals and families managing chronic disease. The purpose of this study was to describe how women with asthma address cost-related challenges to management of their condition.

Methods—In 2012 and 2013, four focus groups were conducted in Southeast Michigan with 26 African American women with asthma, recruited based on maximum variation sampling procedures. A semi-structured interview protocol was employed by trained facilitators. Coded transcripts were analyzed for themes regarding means to reduce the impact of the cost of asthma management.

Results—Major themes identified were acceptance of the status quo; stockpiling and sharing medicines; utilizing community assistance programs; reaching out to healthcare providers and social networks for help; foregoing self-management; and utilizing urgent care.

Conclusions—Awareness of strategies that are helpful to patients in reducing out-of-pocket costs may better equip service providers and others to develop interventions to make useful strategies more widely available.

Keywords

Adherence; asthma; barriers; disparities; self-management

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Declaration of interest

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Introduction

Management of a chronic condition by the patient and family can be perceived as financially burdensome. This is especially true in an economic climate where rising healthcare costs have eroded the comprehensiveness of health insurance and greater out-of-pocket expenses are evident for many individuals. Asthma is one such common chronic condition where financial burden is high among individuals and families despite the provision of health insurance [1–4].

Rising costs of prescription drugs over the past decade has led to some availability of programs to assist patients to access affordable therapies for chronic diseases [5]. Such programs are often sponsored by pharmaceutical and medical device manufactures. Other work suggests that the use of such programs has risen over time; however, disparities in the utilization of these resources are evident, with individuals reporting lower income less likely to use programs [6]. These disparities may be marked by awareness of such programs or access difficulties.

In the general medicine literature with predominately non-Hispanic white samples, the most common strategies utilized for cost-related concerns are switching to a generic drug, using office samples, and discontinuing nonessential medicines [7,8]. The range of what individuals are actually doing to manage their economic reality is not well understood.

African American women with asthma comprise a vulnerable population where experiences addressing health-related financial challenges merit particular attention. They are disproportionately affected by asthma, face the greatest challenges with self-management, have disproportionately high urgent care use for asthma and experience worse asthma health outcomes compared to other subgroups regardless of socioeconomic status [9]. They have increased asthma-related risk exposures to both indoor and outdoor materials influencing allergic response and may be vulnerable to financial burden with asthma management. They may confront unique barriers due to racial and gender disparities in economic opportunities and communication with healthcare providers [10]. African American women, therefore, comprise an important population providing insights into how the costs associated with disease management are handled. The objective of this study presented here was to take a preliminary and qualitative look at the range of ways health-related financial challenges to asthma management are being addressed in a vulnerable population.

Methods

Sample

Participants were identified from the control arm of a randomized control trial (RCT) evaluating a self-management program for women with asthma [11]. Participants were African American women 18 years of age or older with physician-diagnosed asthma based on National Asthma Education and Prevention Program Expert Guidelines [12]. In 2012, participants were recruited from clinics within the University of Michigan Health System (UMHS), through Blue Cross Blue Shield of Michigan and through the community. Study eligibility criteria for participants in the RCT were as follows: (1) female, (2) self-identity as

African American, (3) 18 years of age or older, (4) listed on the UMHS Asthma Patient Registry, a validated all-payer registry of patients with persistent asthma cared for within the UMHS, or within the asthma registry of Blue Cross Blue Shield of Michigan, or receive care through the UMHS or a provider contracted with Blue Cross Blue Shield of Michigan, (5) access to a telephone and (6) not pregnant. The protocol for this study (Ame00026060 for HUM00033784) was approved by the Institutional Review Board at the University of Michigan Medical School.

Participants identified in the baseline survey interview in the RCT who reported a preference to discuss their out-of-pocket costs with their healthcare provider were re-contacted *via* recruitment letters and follow-up phone calls for participation in one of four 90-minute focus groups. This measure was used as a proxy to identify individuals for whom the financial aspects of asthma management may be particularly important.

Focus groups were carefully composed based on maximum variation sampling procedures [13], whereby each focus group was homogenous, based on their health insurance status (full or partial/no coverage), and heterogeneous, based on variation in self-report responses to the presence of multiple morbidities, perception of financial burden, frequency of discussing out-of-pocket costs with a healthcare provider and years since their initial asthma diagnosis from the baseline survey interview. Based on average out-of-pocket costs associated with types of health insurance available in the US [14], participants with private insurance, Medicare only and no health insurance were classified as having “partial/no” insurance, and participants with Medicare and supplemental coverage, Medicaid, military health care, Indian Health Service and other government program were classified as having “full insurance”.

Of the 100 participants who met inclusion criteria for the focus groups, 60 were randomly selected for contact. Sixteen agreed to participate in the partial/no insurance groups; of them, 15 participants provided consent. In the full insurance groups, 17 individuals agreed to participate and 11 provided consent. Of the remaining participants who were included in the sample, 7 refused and 20 could not be contacted. All individuals who participated in the focus groups provided written informed consent and were given modest monetary compensation for their participation.

Focus group design and data collection

The moderator’s guide was designed to elicit information regarding financial-related perceptions and experiences addressing cost-related challenges with asthma management. Twelve questions and prompts were developed.

Participants were asked about ways in which they manage costs, including experiences speaking with their healthcare providers about financial concerns, experiences with resources in the community and other strategies that have been helpful to them in alleviating health-related financial concerns. A content review of the protocol questions was conducted with experts who have extensive experience working with the target population.

Each focus group was led by two facilitators who were also women of color. One facilitator was the primary author, and the other facilitator, a social worker and health educator, has extensive experience leading focus groups and working with the target population. A note taker took field notes, and all discussions were audio-recorded. Research assistants were responsible for ensuring that all participants completed informed consent, a survey of demographic information, setting up refreshments and providing child care. Consistency of procedure was assured across the groups through the use of the standardize interview protocol and systematic training of facilitators and note takers. Facilitators welcomed and thanked participants for their time and recommended established ground rules for discussion [15]. Each facilitator initiated half the questions in the discussion guide. Both encouraged spontaneous discussion, clarified concepts and questions and actively solicited participation from less-vocal participants.

Analysis

To check for transcription accuracy, a review of the focus group transcripts and audio recordings was conducted. Preliminary codes were generated based on a review of each transcript to identify statements reflecting recurring distinct categories, concepts or themes regarding experiences with addressing financial-related challenges with asthma management. Codes were refined as needed and transcripts were recoded to reflect the refined codes. Reliability was assessed by checking transcripts for obvious mistakes and spot-checking data with codes during the coding process to ensure that there was no drift in the code definitions [16]. NVivo 9 software (Doncaster, Australia) was used to organize codes.

Transcripts were coded by two independent coders (focus group facilitators). All coding was reviewed, and the two coders met to resolve coding differences. Interrater reliability for the categories was assessed using percent agreement (number of observations agreed on divided by the total number of observations) and Cohen's Kappa. Since percent agreement does not account for agreement that could be expected to occur by chance, reliability using this measure alone may overestimate true agreement [17]. Therefore, Cohen's Kappa was used as an additional assessment of interrater reliability to account for agreement based on chance. Cohen's Kappa is commonly used in research that involves the coding of behavior [18]. Interrater reliability based on percent agreement was found to be 98%, and with Cohen's Kappa, the proportion of agreement was found to be appropriate for exploratory work ($\rho_0 = 0.79$).

Coded questions from focus groups were used to generate themes that described experiences addressing financial-related challenges with asthma management. Comparisons and differences in themes were made between the experiences of individuals with full health insurance coverage versus partial/no coverage.

Results

Qualitative sample characteristics

The mean age of participants ($n = 15$) in the partial/no insurance group was 47.53 years ($SD = 10.96$) and 44.36 years ($SD = 12.04$) in the full insurance group ($n = 11$). Two-thirds of participants in the partial/no insurance group and 20% of participants in the full insurance group had college and above levels of education. In the partial/no insurance group, two-thirds of participants had an annual household income less than \$40 000, whereas 81% of the participants in the full insurance group reported this level of income or lower. Of those in the partial/no insurance group who had insurance, 80% reported having private insurance and 20% reported no insurance. In the full insurance group, 36% had Medicare and supplemental coverage, 27% had Medicaid only and 37% had other forms of government insurance.

Mean years since asthma diagnosis was 14 years ($SD = 10.96$) for the partial/no insurance group and 17 years ($SD = 11.10$) for the full insurance group. Mean number of other chronic conditions was 4 ($SD = 2.95$) for both groups.

A major difference between the two groups concerned asthma related out-of-pocket expenses. For the partial/no insurance group, mean out-of-pocket expenses a year was \$449 ($SD = 571.99$) and \$24 ($SD = 34$) for the full insurance group. Financial burden with asthma management was reported by 80% of the partial/no insurance group members and three-quarters of the full insurance group members.

Qualitative responses from focus group members revealed a range of strategies used to address cost-related challenges with asthma management. Five distinct themes emerged from the data (see Table 1). Participants described acceptance of the status quo; planning ahead, stockpiling medicines and sharing medicines; utilizing community assistance programs; reaching out to healthcare providers and social networks for help; foregoing self-management; and utilizing urgent care.

Domain 1 – acceptance of the status quo—Participants most commonly described addressing their asthma-related financial challenges through passive acceptance. Some participants expressed high self-efficacy with managing their asthma, even in the face of hardship, given that they had been managing the condition for a very long time. Others described their current situation as better than the alternative (e.g. not breathing, paying full price for medications) and accepted the status quo as indicated by phrases such as “grin and bear it” or “it is what it is”. They reported consciously ignoring the financial burden for the sake of keeping their asthma under control. Prayer was commonly mentioned as a way of making the acceptance of financial stress easier.

A middle-aged woman with low-income and Medicaid coverage noted:

“When I get into a financial situation, I sit right here on this couch, and I pray about it, and don’t think no more. Because you know why? Like I tell Him, they bills gonna be here when I’m dead and gone”.

Domain 2 – planning ahead, stockpiling medicines and sharing medicines—

Several participants mentioned that they stockpiled medicines, planning ahead for times when they themselves or a family member with asthma may be in need of medication but may not have the means to purchase it. Women described refilling prescriptions, including controller and rescue medicines, regardless of immediate use. One woman with private insurance who also had children with asthma noted:

“I know there was a gap between jobs where I had no coverage, but I knew it was coming. So, I found myself stockpiling medication. I had (laughs) an arsenal. I made sure those prescriptions got filled – even if I didn’t use it. And I make sure my kids have it, too”.

Participants also described sharing medicines with their children and family members in the event that financial burden precluded obtaining medicines for asthma within the family unit.

A middle-aged woman with Medicaid described sharing her medicines with her grown children, whom often struggled with maintaining their own continuous insurance coverage:

“You know, sometimes my kids, because they have asthma, so I give them an inhaler, if I have too many inhalers – because my kids don’t have insurance. My daughter...had asthma so bad and her inhalers were so high, so I would give her mines. And then, since I have insurance, I would go get extra inhaler for me and go give her one, you know, for her. So, I mean, you got to do what you got to do. And I make sure my kids have it, too”.

Domain-3 – utilizing community assistance programs—Themes emerged related to participants’ experiences using community assistance programs. Benefits of community assistance options to address cost-related challenges with asthma therapies were noted by several participants. Participants described both government and pharmaceutical company programs that specifically subsidize the cost of asthma medicines or provide free medicines. Others also described local public insurance programs that offer coverage for those who are episodically uninsured.

Participants’ experience in using such programs included both lack of advertising for such programs and the relative ease of navigating programs once they are found. One woman with Medicaid, who experienced episodes of not having insurance in the past, described accessing pharmaceutical assistance programs and how they are much more accessible than they use to be:

“There’s a website you could go to, and it will pull up every single, pharmaceutical, every medication that you can click on, you know, it will take you to the company that makes the medication and whether or not they have a program. So, it’s just one website address you can go to, and pull up every medication, every pharmaceutical there is. You click on it. Now it’s easy. Five years ago, it wasn’t. Five years ago, nobody told you about these programs, and you had to find out on your own. And the pharmaceutical companies didn’t have them. But now they have, they have special programs for people who are under-insured or not insured at all. So, today it’s very easy”.

Participants with low-income and government-sponsored insurance described qualifications for assistance programs available for people with low income. Participants mentioned that paperwork typically requires authorization from social workers and/or physicians documenting the chronic condition and need for assistance. They also mentioned that paperwork does not often require a lot of documents and typically consists of proof of employment, a paystub or W2 form if one is generating income. For those unemployed or without sources of income, no further paperwork is required. Participants mentioned that their experience with assistance programs is that staff members are often accommodating and willing to work with individuals in obtaining the documentation needed to demonstrate need.

Domain 4 – reaching out to healthcare providers and social networks—Many participants mentioned that they reach out to their healthcare providers and social networks to address financial concerns with asthma. Participants most often identified their physician and social workers as most helpful in assisting with financial issues. Other members of the clinical care team identified as supportive were nurses and pharmacists. One woman with private insurance noted that her provider was accommodating to her financial concerns:

“Um, there have been times a doctor suggested something”, and I say, “you know, I just, I don’t think I can afford that at this time”. “So, let me see if there’s another option for you.” And they’ll, they’ll look to see if there’s something that’s accommodating or similar, um, much cheaper”.

A theme emerged among individuals with partial/no insurance regarding the importance of negotiating ways to reduce out-of-pocket expenses with a healthcare provider. Participants noted “If you ask them, they’ll do it” (e.g. change the therapeutic recommendation to a low-cost option), “Everything is negotiable”, “It’s your health. You have to look out for yourself”, “It’s also your money” and “If you don’t ask, you don’t know the answer’s already no”. Participants experienced in negotiation expressed their confidence in engaging in negotiation with their provider around cost.

Participants described several options offered by clinicians in order to manage the financial burden associated with their asthma management. Participants asserted that their physicians will write prescriptions for as many of their medications as possible, including vitamins and over-the-counter drugs, so that their health insurance covers those costs. Several participants noted that when they expressed concerns about their out-of-pocket expenses, they were offered an affordable, alternative treatment option. Some participants with private insurance mentioned that their physicians offer them options to make payments on their co-pay or full cost medical bills or gave them options for renting medical equipment (such as a nebulizer). Office samples were most often mentioned as a helpful option that both physicians and pharmacists offered to their patients on request.

Participants also mentioned that they rely on their family and social networks to assist with health-related financial concerns. An older woman with private insurance mentioned:

“...And any time my sons think I want or need anything, they provide it without me asking. Or the Lord. You know, so, I can’t complain”.

Domain 5 – forego self-management and seek urgent care—Some participants expressed that because of cost, they forego self-management of their asthma and handle acute situations as they arise by seeking services from urgent care facilities. A common behavior participants reported was doing without medicines. These behaviors were described among those for whom insurance coverage was episodic, absent or inadequate. One woman with private insurance she obtained through her employer mentioned foregoing her medicine when she was uninsured in the past:

“Yeah, I’ve gone a year or two without taking medication all together just because I didn’t have insurance. If I don’t got it, I can’t. I ain’t got money”.

Discussion

To our knowledge, this is the first study to use focus groups to understand experiences addressing cost-related challenges with managing a chronic condition in a vulnerable population, specifically African American women with asthma. In the five domains that emerged, we found that patients face difficult problems regarding the cost of management and a range of strategies are used to manage health-related financial concerns, regardless of degree of health insurance coverage, education or household income. Other work suggests that compared to whites, African Americans have been found to have higher levels of resourcefulness in the face of life stressors [19].

Some strategies that were reported appear to be effective for women in this study and may prove to be beneficial if more widely available through information and education. Office samples were helpful to patients and coupons, vouchers and mail order prescriptions may also be equally helpful and receptive to patients. Among individuals with asthma, the lack of publicity of community health programs that offer assistance with the cost of management may pose difficulties to potential users in terms of accessing information that may preclude them from being aware of their full range of options. Barriers to accessing and navigating online information tools (e.g. literacy and fewer economic resources) may also preclude individuals from accessing community resources. These barriers necessitate patient-provider dialogue around financial-related concerns in order to improve equity in access to assistance programs. Given that some programs require verification by a healthcare provider, communication appears essential in order for patients to obtain low-cost options. The healthcare provider role in patients’ access to assistance programs may also necessitate greater capacity to assist care teams in addressing these issues in their practice settings.

Despite the infrequency of communication about health-related cost concerns documented within the general population, and disparities in communication with health care providers in historically marginalized groups ([8,20]), some African American women with asthma in this study appear to communicate their cost-related concerns to their healthcare providers and rely on them as a source of alleviating such challenges, but they were in the minority. This observation has implications for the development of health education interventions that can be adjuncts to medical treatment. Such approaches have been shown to be both cost-effective and valuable for individuals receiving information and behavioral skills training [21]. Interventions may provide a venue to learn about obtaining low-cost care options in

complex health systems using experienced peers who know how to negotiate in a clinician–patient context that is historically hierarchical and patriarchal. Peer-led group interventions for accessing cost-reducing strategies may be especially effective for individuals who face problems because of inadequate health literacy or face challenges accessing and utilizing information technology.

Some strategies that were utilized by participants are likely harmful and may lead to serious long-term complications in individual’s health states and to greater health system costs, such as stockpiling and sharing medicines. These findings may also have implications for measuring medication adherence, particularly with asthma management. Although suggested gold standards for measuring medication adherence include dose and pill counting and canister weighing, as well as electronic pharmacy records of refill data [22], our qualitative findings suggest that such measures may not be adequate proxies for true adherence behavior, especially among individuals and their families who face financial-related concerns with asthma self-management. Existing measures of medication adherence may require further exploration that takes into account “survival”-related behaviors. Some participants reported forgoing self-management of asthma as a result of financial concerns. Numerous studies show that individuals with chronic conditions forego self-management due to high cost and such behavior impacts health outcomes [9,23–25].

Among African American women, acceptance of the status quo appears to buffer health-related financial burden with asthma management and prayer assists with this acceptance. These findings are consistent with other work suggesting the prominence of high levels of religiosity and coping behaviors within African American communities [26]. It is not clear whether acceptance of the status quo may be an adaptive or maladaptive coping strategy for participants. John Henryism, which is a coping strategy to exert energy and maintain constant vigilance in the face of barriers, has been linked to poor health, especially within communities that have been historically marginalized [27]. On the other hand, high personality hardiness, a multifaceted personality construct consisting of feelings of control, commitment to self and work and feeling challenged in the face of change [28], has been shown to buffer the effects of stress on illness among women compared to low hardiness women [29]. Studies that make clear the effects of such cognitive and emotional strategies on asthma outcomes may aid the development of relevant interventions.

This was an exploratory study with a small number of participants intending to generate qualitative descriptions of patients’ cost management strategies. It has several limitations. Financial concerns and how they are addressed can be a sensitive topic, and participants may not have been comfortable answering such questions or discussing their health-related financial situation in a focus group. The classification of types of health insurance in broader categories of “full” and “partial/no” insurance may not reflect these evolving trends. For individuals with asthma with all types of insurance, the now implemented Patient Protection and Affordable Care Act (PPACA) may strengthen access to community assistance programs, communication with health care providers and potentially reduce the number of individuals foregoing self-management. Necessary medicines and medical equipment will have nominal to no co-payments, and healthcare delivery organizations will be incentivized to better coordinate care and improve outpatient care. Given that a greater number of people

with asthma will be able to access health insurance and the viability of the PPACA may continue under political debate, individuals may likely continue to plan ahead, stockpile and potentially share medicines. Finally, the study sample comprised African American women receiving care in Southeast Michigan. Findings may not be generalizable to all women or adults with asthma or those receiving care in other regions. Despite these limitations, findings from this study provide insights regarding problems people with chronic conditions confront and ways they try to reduce their impact.

Conclusion

In addressing health-related financial challenges with asthma management, the African American women studied used a range of cost-reducing strategies. Awareness of strategies that are helpful to patients in reducing their financial burden may better equip program developers to design interventions to make useful strategies more widely available. Potentially harmful strategies, such as forgoing self-management and sharing medicines, may require additional policy solutions related to insurance coverage. Providing effective alternatives to costly clinical regimens appears warranted.

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Table 1

Major domains identified in focus groups with women with asthma about what they are doing to address health-related financial challenges with asthma management.

Domain	Descriptors	Example
Acceptance of the status quo	Passive acceptance of the situation and cognitive appraisals of considering alternatives were described as helpful in managing asthma despite financial hardship. Prayer assisted with this acceptance for some individuals.	“if you get stressed out about it, then your asthma gonna get worse. It gets worse. Put it in the pile. Like you can't just sit there and just be over-defeated about all the medical bills because you have to focus on what you can do. So, I'm like I can pay my rent, but I cannot pay this \$2000 bill, so I'm not gonna get upset because I'll be right back in the hospital. And start to get more \$2,000 bills. So, might as well don't even worry about it. I'm gonna do what I can do”.
Stockpiling medicines	Keeping an abundant supply of medicines was helpful in preparing for times when affordability concerns may arise.	“I keep so much medication, I'm the pharmacy. What I do, I just go through it every season. You know, I keep down the dates, and I throw them out”.
Utilizing community assistance programs	Community assistance programs were easy to navigate for some participants in order to obtain low-cost or free medicines, while others were unaware of these options.	“They don't require a lot of documents. And the people that handle it are very, um, accommodating. So, because they want you to – that's what the money is for. So, they want you to get access to it. So, they're very accommodating. You know? I think the only, um, documents you have to provide is, uh, if you have a W2 form, um, if you're employed, um, um, your check pay check or something. That's what I did. I had zero. You had zero income, and that's good. You don't have to go any further than that”.
Reaching out to health care providers & social networks	Negotiating out-of-pocket payments with health care providers and pharmacists, initiating these concerns and relying on family members were ways in which participants social networks and care teams were described as a helpful resource in addressing cost-related concerns. These networks provided several helpful options including payment options, renting equipment, utilizing office samples of medicines.	“when I didn t have insurance, that gap, I let my doctor know ahead of time, so I was able to negotiate with her how much I was gonna pay for that visit. I say everything is negotiable. That s the way I look at it.”
Foregoing self-management and seeking urgent care	Decisions are made around foregoing routine care and medicines, and obtaining needed care through urgent care facilities.	“when you don t have insurance, the way you manage asthma is through the emergency room. So, you will literally wait until you have to go –an attack, and the only way you can get medication is to go to the emergency room.”