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Beyond co-pays and out-of-pocket costs: perceptions of health-related financial burden in managing asthma among African American women

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Abstract

Objective—The purpose of this study was to define perceptions of health-related financial burden based on the views of individuals who report these perceptions through qualitative approaches.

Methods—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 was employed by facilitators. Coded transcripts were analyzed for themes regarding dimensions of the meaning of financial burden.

Results—Major domains of financial burden identified included (1) high out-of-pocket expenses; (2) lost wages from exacerbations, inability to maintain a stable job and stress from making decisions about taking a sick day or coming to work; (3) transport costs; (4) both costs and stress of managing insurance eligibility and correcting erroneous bills.

Conclusion—Greater awareness of factors that add to perceptions of financial burden might better equip researchers to develop interventions to help care teams manage such concerns with their patients.

Keywords

Asthma; health insurance; illness and disease experiences; risk factors

Introduction

From a policy perspective, there is an assumption that economic resources and the provision of health insurance mitigate the majority of access-related challenges. However, national

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Declaration of interest

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data show that nearly one in five families report financial burden with health care, and nearly a third of them have some form of health insurance [1]. These estimates are based on perceived ability to pay medical bills.

There are several ways in which financial burden is conceived in the existing literature, which has implications for identifying those at risk for poor health outcomes and targeting interventions and policies. Banthin and Bernard define objective financial *burden* as a comprehensive and policy-relevant measure of health care spending that sums all expenses resulting from individual and family-level decisions to enroll in health insurance coverage or obtain medical treatment [2,3]. Financial burden is also defined as including out-of-pocket healthcare expenses as a rising percentage of income [4]. Some existing data sources such as the Medical Expenditures Panel Survey quantify the range of health-related out-of-pocket expenses that individuals incur that provide a reasonable understanding of the components evident in objective assessments of health-related financial burden such as medicines, transportation costs, cost of health care visits. The literature conceptualizes financial *barriers* as an inability to access care due to cost [5], which is a behavioral or coping response to a real or perceived financial barrier in terms of access to care [6].

Few studies, however, have examined or measured *perceptions* of financial burden as a multi-faceted construct that may influence care-seeking and may not always be identified with the aforementioned objective measures. Measures that assess perceptions of burden or stress tap into an individual's appraisal of whether the events they encounter are threatening, taxing or potentially overwhelming to their existing coping resources and provide cues about individual environmental demands, their evaluation of events in their life or their ability to cope [7]. Measures related to perceptions of financial burden in existing studies are primarily used to assess impact of medical bills and out-of-pocket costs and do not always differentiate episodic from chronic care [8,9]. Thus, they may miss potential financial-related stressors unique to chronic disease management. These are important to understand given that nearly one in two people are now living with a chronic condition [10], which often requires lifetime management with a therapeutic regimen and routine clinical follow-up.

Existing conceptualizations of health-related financial burden are limited because they presume that financial burden can be measured solely in economic terms. The actual financial circumstances of patients and families do not fully explain their perceptions or disease management behaviors as they relate to the cost of care. Some data support this assumption. High-income patients have been shown to report cost-related non-adherence to their medical regimen [11]. This finding underscores the idea that factors beyond actual economic circumstances and access to care may affect perceptions of the financial burden of disease management, and thus subsequently impact patient health.

We initiated this study to further understand financial burden from the views of individuals with chronic disease, specifically asthma. We hypothesized that perceptions of health-related financial burden might be a multifaceted construct that includes not only economic resources but also other factors such as the management health insurance as supported by findings from qualitative work in international settings examining patient perspectives of economic hardship among the chronically ill with significant disability [12].

Asthma in vulnerable populations provides a unique case condition to examine components of health-related financial burden as perceived by individuals living with chronic disease through qualitative approaches. It is a common chronic condition with significant health care costs to individuals and society. Several studies have shown that health-related financial burden is significant among people with asthma [5,13]. Since perceptions largely influence behavior and outcomes in care [14], a better understanding of what these financial-related perceptions entail in the context of chronic disease management might provide more insight on how to better assess the size and distribution of the population at risk for poor health outcomes that may manifest from these burdens as perceived by individuals who experience them.

Methods

Sample

Participants were identified from the control arm of a randomized control trial (RCT) evaluating an asthma self-management program for African American women. Recruitment and inclusion criteria for the RCT are described elsewhere [15]. The protocol for this study was approved by the Institutional Review Board at the University of Michigan Medical School.

Design and data collection

Participants were adult African American women with physician diagnosed asthma based on National Asthma Education and Prevention Program Guidelines [16]. In addition to meeting the inclusion criteria for the RCT trial, inclusion criteria for the participants in the focus groups were individuals identified in the baseline survey interview who reported that it was important to them to discuss financial concerns with their clinician. These individuals were re-contacted for participation in one of four 90-minute focus groups. Of the 100 participants who met inclusion criteria, 60 were randomly selected for contact. Sixteen individuals agreed to participate in the partial/no insurance group; of them, 15 participants provided consent. In the full insurance group, 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 participants provided written informed consent and were given modest monetary compensation. Focus groups were carefully composed based on maximum variation sampling procedures [17], whereby each group was homogenous based on their health insurance status (full or partial/no coverage) and heterogeneous based on variation in self-report responses to clinical characteristics. Based on average co-pays [18], participants with private insurance, Medicare only and no insurance were classified as “partial/no” insurance, and participants with Medicare with supplemental coverage, Medicaid and other government were classified as “full insurance”. Other government insurance included programs administered through the state of Michigan and local counties, as well as military coverage and Indian Health Service.

The moderator’s guide with 12 questions and prompts was designed to elicit conversation around financial perceptions about asthma management and related services. Examples of questions from the discussion guide are seen in Table 1. Participants were asked about things

that cost them money to manage their asthma that the health insurance company or their doctor might not know about. A content review of the questions was conducted with experts with extensive experience working with the target population. Each focus group was led by two facilitators who were also women of color: the primary author and a social worker who had extensive experience working with African American women. Consistency was assured across the groups through the use of a standardized interview protocol. Both focus groups were audio-recorded. Both facilitators established ground rules, initiated questions in the discussion guide, encouraged spontaneous discussion, clarified concepts and questions and actively solicited participation [19]. Data saturation was reached after four focus groups, two each with the partial/no and full insurance groups.

Analysis

To check for transcription accuracy, a review of the transcripts and audio recordings was conducted by the primary author. Preliminary codes were generated based on a review of each transcript to identify statements reflecting recurring distinct themes regarding aspects of financial burden with asthma management. Codes were refined and transcripts recoded as needed. Reliability was assessed by checking transcripts to make sure they did not contain obvious mistakes and spot-checking data with codes to ensure that there was no drift in the code definitions [20]. NVivo 9 software (Burlington, MA) was used to organize codes.

All transcripts were coded by two independent coders (focus group facilitators) who met to resolve coding differences to enhance reliability. Interrater reliability for the categories was assessed using Cohen's Kappa was found to be appropriate for exploratory work ($k = 0.79$). Coded questions were used to generate themes regarding dimensions of financial burden. Comparisons and differences in themes were made across groups as appropriate.

Results

Table 2 describes characteristics of participants from the focus groups ($n = 26$). Four distinct domains emerged from focus group discussions (Table 3).

Domain 1: out-of-pocket expenses

Out-of-pocket expenses were mentioned most often in describing perceptions of financial burden, especially with asthma medications. Although there was a magnitude of difference in the total out-of-pocket expenses per year on medicines reported between the full and partial/no insurance groups (Table 2), qualitative observations showed similarity in perceptions between the two groups. There was consensus across groups concerning the fact that many asthma medications do not come in generic form, and that patented "brand name" medicines contribute to high out-of-pocket costs. Others described the number of inhalers they were prescribed, and the co-payment for each inhaler as particularly burdensome. There were differences by type of insurance. Some individuals with full insurance reported \$1–\$5 monthly co-pays, while others with private health plans reported spending as much as \$500 per month, which amounted to \$6000 out-of-pocket on asthma medications in one year. Across groups, participants described their out-of-pocket costs with medicines as "ridiculous", "outrageous", "very expensive", "costly" and "such a waste". Participants in

the partial/no insurance groups also noted high out-of-pocket expenses for medications to manage other chronic conditions.

Participants in the partial/no insurance groups reported that environmental modification was expensive and not often covered by health insurance. They noted examples such as central air conditioning, air filters and purchasing specific cleaning products. Participants also expressed that urgent care use for asthma was another source of high expense.

Domain 2: lost wages

Several participants in the partial/no insurance groups reported missed opportunities for earned income contributing to their perceptions of financial burden. They especially noted lost work time because of asthma exacerbations. Participants expressed concern with needing to make decisions about using sick days and inability to maintain a stable job. They mentioned that once sick days were exhausted, they were borrowing sick time.

Domain 3: transportation costs

Across groups, themes also emerged around transportation to health care or administrative facilities contributing to perceptions of financial burden. There was consensus regarding these sentiments, especially in the partial/no insurance groups where they noted that the cost of an ambulance was several hundred dollars out-of-pocket during emergencies.

They also noted that urgent care facilities are more affordable than emergency departments, but were not always close in proximity, requiring a rapid, potentially stressful calculation to assess the cost of care, the quality of care and the cost of transportation to care. For the full insurance groups, distance was described as not just entailing the use of health care services but also the acquisition and management of health insurance. In the full insurance groups, some women described the cost of gas to drive to administrative offices for government-sponsored insurance as expensive.

Domain 4: managing health insurance

Participants across groups described several aspects of health insurance as contributing to their perceptions of financial burden. They described fear of exceeding coverage and gaps in coverage. Many participants with private insurance experienced variability with asthma therapies covered on their health insurance formulary, changes in formulary and difficulty obtaining this information. There was consensus among participants across groups regarding health insurance as a source of uncertainty in managing their asthma in terms of both covered services, as well as retaining coverage. Individuals with full insurance especially described administrative challenges with their coverage. Uncertainty with coverage was described with Medicaid in the context of administrative turnover that delays paperwork to keep coverage active. Finally, although individuals with Medicaid described nominal out-of-pocket costs with asthma therapies, several participants with this plan expressed challenges with the time required to reconcile erroneous medical bills.

Discussion

To our knowledge, this is the first study to use focus groups to gain insight of what entails perceptions of financial burden among adults with chronic disease, specifically asthma. We found that while high out-of-pocket expenses contribute to perceptions of financial burden, suggesting that perceptions might align closely with objective measures, there were a variety of issues causing perception of financial burden that could not be characterized or counted as out-of-pocket costs.

Across our focus groups comprised of individuals with all types of health insurance, we found that maintenance of insurance eligibility is a component of financial burden perceived by individuals and is consistent with findings from international settings [11]. In addition, the stress of managing insurance interacts with the stress of uncovered expenses to magnify the sense of burden. Measures that only assess financial burden in economic terms or affordability may underestimate financial burden in the population and may miss people who regard the management of their health-related finances and insurance as stressful and therefore a component of burden, despite ability to pay or access care based on objective information.

The changing economy and healthcare infrastructure provides a context for these findings and potential explanations to pathways of burden. Over the past decade, the rising costs of health care in the United States has been met with a decline in the affordability and quality of insurance in both the private and public sectors [21]. As a result, many people frequently cycle between public and private insurance programs and navigating these infrastructures may be stressful. These navigation issues may be further magnified in the population with recent Affordable Care Act reforms and health insurance exchanges that will require far less administrative assistance to sign up and maintain coverage than historically evident. Although the Affordable Care Act provides greater clarity of where individuals should explore insurance options based on their situation (e.g. private or public market), it will not solve the problem of cycling between private and public coverage for those below the age of 65 years since public coverage is sensitive to changes in income, which changes over time [22].

The administrative infrastructure for public insurance itself can cause unique financial burdens. In the public sector, the fragmented oversight and funding of safety net programs such as Medicaid contributes to frequent interruptions of coverage for beneficiaries. These interruptions can themselves create out-of-pocket expenses, lost wages and transport costs both for actual health care during lapsed coverage and for the process of reestablishing coverage. Because individual states do not have the fiscal resources to fully implement public coverage programs, they employ administrative barriers or change eligibility criteria frequently to reduce or manage costs [23]. Individuals covered under safety net programs face unique challenges with health insurance beyond those related to accessing health care services, such as physically going to an administrative office to sign up or renew coverage.

There are limitations in this study. Finances can be a sensitive topic, and participants may be uncomfortable answering such questions or discussing their financial situation in a focus

group. Given changes in federal and state health insurance programs characteristic of an unpredictable economy and the recent passage of the Affordable Care Act, the classification of types of health insurance in broader categories of “full” and “partial/no” insurance might not reflect these evolving trends. Finally, the study sample comprised African American women receiving care in Southeast Michigan. As a result, findings might not be generalizable to all women or all adults with asthma or those receiving care in other regions. However, their needs related to the financial aspects of asthma management are not much different from other groups who also report these concerns [5,13].

Despite these limitations, findings from this study have implications for population health, research and clinical practice. Managing health insurance as a source of stress perceived in the context of financial burden is important for health status, given what is known about the adverse consequences of stress on physical health [14]. For individuals managing chronic conditions, stressors may exacerbate existing morbidity and further magnify both perceptions and objective financial burden for individuals and families.

Most research on health-related financial burden has quantified the level of burden across the population in purely economic terms. Future research that also considers the financial stress of managing their health as burdensome regardless of access and ability to pay may lead to measures that can better inform public health and policy efforts around identifying and mitigating these burdens. Comprehensive measures that consider both economic factors and the management of health insurance should be developed when measuring financial burden.

Implications of this work for behavioral interventions and clinical practice include the ability to better understand how financial burden can manifest for patients. A vulnerable population with asthma expressed unique needs that might be apparent in the larger population that healthcare providers might need to prepare to address. Care team awareness of the variety of sources of perceptions of financial burden beyond out-of-pocket costs might better equip them to provide patient-centered care. These findings can inform interventions to assist care teams to efficiently address these issues in the face of competing demands in a busy clinical service load.

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Table 1

Examples of questions from the focus group discussion guide.

How long have you been living with asthma?

Recently, what are some things that have been going well for you in terms of your asthma management? [Probe: have you had less symptoms lately because of something new you may be doing?]

Sometimes it is difficult to take asthma medicines or follow everything the doctor tells us to do because of other responsibilities we may have. What are some things that have made managing your asthma difficult?

Sometimes the amount of money it costs us to take care of our health can add up and be a lot, even if we can afford it or not. What are some things that cost you money to manage your asthma that the health insurance company or your doctor may not know about? [making changes in your household, driving to the pharmacy, cleaning in a special way, only buying certain types of products, etc.]

Copays are changing and sometimes we do not even know that this is happening until we are at the pharmacy or sent a bill in the mail and we need to pay for our medicines or services. What I want to ask you now is how easy or difficult is it for you to get everything you need in order to manage your asthma? What are some examples of your experiences?

What are some barriers or difficulties in getting what you need to manage your asthma? [e.g. changing health insurance plans: being on and off Medicaid]

We were just talking about the money that you have to spend out-of-pocket for your asthma. But you also have other financial responsibilities that you have to take care of for you and your family. How does this affect your ability to manage your asthma?

Many people have to move around their financial responsibilities to make everything work for them and their family. What kinds of things do you have to switch around? How much "clever management" do you do to make this all work?

What are some things that you are or feel responsible for at this point in your life?

What are some things that are important to you or a necessity alongside managing your health?

Is there anything else you would like to share with me today?

Table 2

Characteristics of women who participated in focus groups.

Variable	Partial/no insurance focus group % (n = 15) ^a	Full insurance focus group % (n = 11) ^b
Age (mean, SD)	47.53 (10.96)	44.36 (12.04)
Head of household (% yes)	53%	91%
Number of individuals in the household		
1	27%	64%
2	20%	18%
3	33%	0%
4 and more	20%	18%
Educational attainment		
High school/GED or less	13%	30%
Some college, associate's degree or vocational school	27	50%
College or above	60%	20%
Household income		
<\$20 000	18%	73%
\$20001–\$40000	46%	8%
\$40001–\$60000	27%	0
>\$60001	9%	19%
Health insurance		
No insurance	20%	0
Private	80%	0
Medicare only	0%	0
Medicare + supplemental coverage	0	36%
Medicaid only	0	27%
Other government	0	37%
Total out-of-pocket expenses on asthma medicines in a year (mean, SD)	\$449.69 (571.99)	\$24 (34.91)
(Range)	\$0–\$2040	\$0–\$99
Years since asthma diagnosis (mean, (SD))	14.28 (10.96)	17.09 (11.10)
Total number of other chronic conditions (mean, (SD))	3.4 (2.41)	4.72 (3.55)
Perception of financial burden (% yes)	80%	75%

^aPartial insurance = private, no insurance or Medicare only.^bFull insurance = Medicaid, Medicare and supplemental coverage or other government insurance.

Table 3

Major domains identified in focus groups with women with asthma about what encompasses perceptions financial burden.

Domain	Descriptors	Example
High out-of-pocket expenses	Medicines (especially related to asthma), environmental control and urgent care use contribute to high out-of-pocket expenses	"...And when you're an asthmatic, you're often times prescribed Advair, you have to use it monthly, 30 days. So, that's 300-plus dollars a month...in my experience, as a sole practitioner, I had an individual insurance plan that only covered \$2500 worth of, um, pharmaceuticals. Within the first three months of having that, I used up the \$2500 because I had to have four inhalers, with the average cost being about \$250. So, in one year, I spent on medication for asthma, out of pocket, \$5720. Out of pocket, to breathe."
Lost wages	Asthma exacerbations require recovery time that use up paid sick days from work very quickly and contribute to difficulties in maintaining stable employment	"Yeah, it cuts into that time. When I have an asthma attack, I'm off from work for two or three days for sure. It ain't no go to the hospital – and then go to work tomorrow. That don't happen. It's a – you know, you're gonna be off for a couple of days."
Distance to health-related resources	Affordable urgent care facilities and administrative offices to ensure government-sponsored health insurance are often far and the time and gas required are described as expensive	So, it's hard for me right now to have to deal with social services, case workers and paperwork. It's so expensive, and I have to drive all the way to [town in sample region] and drive back. It's just hard, you know, dealing with all of that.
Managing health insurance	Comprehensiveness of coverage, uncertainty with maintaining insurance coverage in a volatile economic climate and false bills contribute to access difficulties with the resources people need to manage their asthma and health	"they'll still try to run out and bill you. Then I'm like, "where did this come from? I got Medicaid. You know?" So, you still have to deal and keep up with your stuff. I still have a lot of bills, even though I have Medicaid, I still have a lot of bills. I call them and try to straighten it out, but then they get, they don't even—And then that's time, on the phone all day – and they all, "hold on. I got to get you to such-and-such." Then you talk to such-and-such. Such-and-such can't help you. You – and next thing you know, you on the phone back and forth for two hours about a medication or a bill that you shouldn't have even been billed for."