EXAMINATION FROM THE PATIENT PERSPECTIVE OF FACTORS AND INFLUENCES OF COST OF CARE-RELATED COMMUNICATION BETWEEN PHYSICIANS AND AFRICAN AMERICAN WOMEN WITH ASTHMA

by

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To individuals and communities whose experiences motivate work

towards health equity and social justice

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ABSTRACT

Asthma is a prevalent chronic condition where associated costs to patients are high and perceptions of financial burden may be evident. Communication between clinician and patient (cost of care-related communication) may mitigate perceptions and improve disease management. Through mixed methods approaches, this dissertation examined 1) economic factors that mediate patient characteristics and perception of financial burden and preferences for cost of care-related communication, 2) associations between cost of care-related communication and asthma self-management behaviors, and 3) clinical factors that mediate communication and asthma-related urgent care use.

Baseline data were collected from 343 African American women seeking services for asthma in Southeast Michigan. Additional qualitative data were collected from sub-samples via two focus groups (n=14) and in-depth interviews (n=25). Mediation was assessed with structural equation modeling. In the first and second study, associations between perceptions of financial burden, preferences for cost of care-related communication, and patient characteristics were examined through hypothesized mediators (household income, health insurance, out-of-pocket expenses). In the third study, the relationship between cost of care-related communication and self-management behaviors and urgent care use was assessed with linear regression models, and structural equation models. Coded transcripts from the qualitative data were analyzed for themes to provide supporting information.

More than half of women with asthma reported perceptions of financial burden. Three-fourths reported a preference to discuss cost with their clinician; however, less than half reported such discussions actually occurring. Household income, health insurance, and out-of-pocket expenses accounted for the relationships between patients' characteristics and their perceptions of burden and preferences for communication. No associations between cost of care-related communication, self-management behaviors and asthma-related urgent care use were found.

Many people perceive financial burden and would like to discuss cost with their clinician, but these discussions occur infrequently, and are often initiated by patients. Burden may be present despite having economic resources. Given the high percentage of women desiring cost-of-care discussions, more research is needed in order to strengthen capacity of care teams and patients in order to integrate financial concerns with disease management into routine care.

CHAPTER 1

INTRODUCTION

In the U.S., 133 million people (one out of every two adults) live with a chronic condition (Centers for Disease Control and Prevention, 2011a). The majority of adults (81%) have health insurance coverage, including an additional 3 million young adults who acquired adult dependent coverage up to age 26 through recent expansions of the Patient Protection and Affordable Care Act (PPACA) (Kaiser Commission on Medicaid and Uninsured, 2010; Kaiser Family Foundation, 2011; U.S. Department of Health and Human Services, 2012). Chronic illnesses are a major contributor to health care costs; the medical care costs of people with chronic illnesses represent 75% of the $2 trillion in U.S. annual health care spending (Institute of Medicine, 2012). The current economic climate indicates that patients will inevitably bear costs associated with health care. These costs can be significant for both the uninsured and the insured when health insurance plans do not provide full coverage for the range of services chronic conditions require. Twenty-percent of the population report serious problems paying medical bills (Schoen et al., 2010), and those with chronic conditions are more likely than their healthier counterparts to report these problems (Cunningham, Miller, & Cassil, 2008; Kaiser Family Foundation, 2005). Gender differences are also evident: three out of five women report difficulties paying medical bills (The Commonwealth Fund, 2009). Compared to men, women require more health care services during reproductive years, have higher out-of-pocket medical costs and lower average incomes, and are more likely to forego care due to cost.

Asthma is a prevalent chronic condition for which adverse health outcomes are common and associated costs are high (Akinbami et al., 2012). Like other chronic diseases, asthma requires lifetime management with a therapeutic regimen and routine interfacing with the health care system in order to sustain functional capacity, productivity, and quality of life. As a result, patients may perceive disease management as financially burdensome.

One third of adults in the general population who have asthma report financial burden associated with managing their condition, and discussion of the cost of care (cost of care-related communication) occurs infrequently in clinical encounters (Kaiser Family Foundation, 2005; Alexander, Casalino, & Meltzer, 2003). This is unfortunate because communication plays an integral role in shaping the relationship between clinicians and patients, and has been shown to affect process and outcomes of care in asthma (Clark et al., 2008; Diette & Rand, 2007; Roter & Hall, 2006). Discussion about cost of care between patients and clinicians may also influence asthma health outcomes, although the pathway through which this occurs has not been examined. This dynamic will be addressed further in Chapters two and six.

Patient perceptions, attributions, and motivations largely influence outcomes in care (Frankel, Quill, & McDaniel, 2003). The stress literature considers perceived stress a dimension of subjective quality of life or psychological well-being, and finds that it better predicts health outcomes than the simple occurrences of stressful life events (Brown, 1988). Perceptions of financial burden based on the individual’s appraisal of their life situations and circumstances justifies further examination because they may have more clinical relevance for intervention to improve patient health than objective assessments of financial burden.

African American women comprise a particularly vulnerable population whose perceptions of financial burden related to health care merit further exploration. They are disproportionately affected by asthma, face challenges with self-management, have disproportionately high urgent care use for asthma, and experience worse asthma health outcomes compared to other subgroups (Centers for Disease Control and Prevention, 2011b). African American women have increased asthma-related risk exposures and may be vulnerable to perceiving asthma management as a financial burden due to persistent racial and gender disparities in economic opportunities (Jackson & Williams, 2006). African American women also present a unique population for examining high-risk cases in which influences of communication with a clinician are most likely to influence key outcomes.

In an era of financial stress, understanding how communication concerning patients' perceptions of health care costs affects outcomes may enable the preservation of health status and has implications beyond the scope of this patient population. The knowledge that communication about possible financial hardship may mitigate some of the effect observed between patient financial burden and health outcomes is important to clinical practice; the potential to expand capacity to provide simple, low-cost improvements in chronic care will enable individuals to take full advantage of available treatments, interventions, and existing assistance programs.

Associations between real and perceived financial barriers and patients’ urgent care use for asthma are now established (Karaca-Mandic, Jena, Joyce, & Goldman, 2012; Patel, Brown, & Clark, 2012; Knoeller, Mazurek, & Moorman, 2011). However, no studies have explored the pathways through which demographic and clinical characteristics influence patient perceptions of financial burden, preferences for cost of care-related communication with health care providers, and whether a discussion of the cost of therapies and recommendations is associated with improved adherence to clinical recommendations and a subsequent reduction in urgent care use.

The primary aims of this dissertation are to identify and describe factors and pathways in a population of African American women vulnerable to poor asthma outcomes. More specifically, this dissertation aims to:

Aim 1: To identify and describe

- a. aspects of disease management individuals with asthma perceive as financially burdensome,
- b. what participants are already doing to address their cost-related challenges with disease management, and
- c. the extent to which participants perceive clinicians have engaged them in discussion of financial burden and related options
- d. who initiates cost of care-related discussions,
- e. options offered to participants by clinicians that have proven helpful.

Aim 2: To identify the pathways through which:

- a. Economic factors mediate clinical and demographic characteristics of individuals with asthma and:
    - i. their perceptions of financial burden with asthma management, and
    - ii. their preferences for discussing the cost of asthma care with their health care provider.
- b. Clinical factors mediate frequency of cost of care-related discussion between clinicians and individuals with asthma, and participants' urgent care use for asthma.

    c. Frequency of cost of care-related communication is associated with asthma self-management behaviors.

This dissertation comprises item-specific, baseline survey data from a randomized controlled trial evaluating an asthma self-management intervention among 343 African American women with asthma, as well as in-depth interviews from a sub-sample of 25 participants, and two focus groups with a sub-sample of six and eight participants in each group (n=14).

This dissertation is in the format of three empirical papers, based on a model of factors and influences of cost of care-related communication and important asthma outcomes. Chapter two describes a conceptual model of influences and outcomes of cost of care-related communication between clinicians and individuals with asthma. Theoretical and empirical support is provided to explain relationships in the model. A literature review of financial burden and cost of care-related communication is also presented, summarizing previous findings and highlighting methodological gaps. Chapter three describes an overview of the data sources used in this dissertation. Chapters four, five, and six are three empirical papers that address the aims of this research. Chapter four describes who perceives health-related financial burden and how these perceptions come about. Chapter five describes who prefers to discuss the cost of their care with their clinician and how these preferences come about, and Chapter six describes cost of care-related communication in the clinical encounter and asthma outcomes. Chapter seven concludes with a summary of the main findings, their significance, and recommendations for research, intervention, and clinical practice.

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CHAPTER 2

LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

The media, journal editorials and commentaries have widely described the challenges patients face with the cost of their medical care and their urge to address these issues in the clinical encounter (Donley & Danis, 2011; Cooke, 2010; Cohn, 2008; Federman, 2004). A search of online databases retrieved 75 published articles that describe this area of research in the context of the U.S. health care system. The objective of this review is to synthesize and critique what is known about the financial burden of care, and assess influences, preferences, frequency, and outcomes of cost of care-related communication in the clinical encounter. The discussion that follows will explore the current state of the literature and identify opportunities for further research in terms of key findings, theories and frameworks, samples, and methodology.

Financial burden

Asthma is a chronic condition that affects 17.5 million adults (Centers for Disease Control and Prevention, 2011). Cost concerns may be especially magnified for people with asthma. Advances in the treatment and management of asthma provide solid evidence that asthma can be effectively managed by individuals via a routine medication regimen and environmental control of symptom triggers (Lara et al., 2002). The common assumption is that economic resources and the provision of health insurance mitigate access-related challenges to managing a chronic condition such as asthma. However, national data show that over 80% of adults with asthma report having health insurance coverage, yet 30% of this group report financial barriers to care (King, 2011). The literature has conceptualized patient financial burden in three different ways: objective burden, perceptions of burden, and behavioral responses to perceived burden. These conceptualizations all have implications for interpretation of findings.

Objective Financial Burden

Banthin et al. 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 (Bernard, Farr, & Fang, 2011; Banthin & Bernard, 1996). Financial burden is also defined as including out-of-pocket healthcare expenses as a rising percentage of income (Riley, 2008). These conceptualizations presume an objective measure of burden. Across studies, 20-50% of patients experience objective financial burden with their health care (Riley, 2008; Banthin & Bernard, 1996). Based on the literature, patient characteristics that predict objective financial burden include older age, low income, possession of non-group health insurance coverage, living in a non-metropolitan statistical area, fair to poor health, having a chronic condition, African American race, marital status of single, lower educational attainment, and diagnosis of cancer (Bernard et al., 2011; Riley, 2008; Stewart, 2004; Banthin & Bernard, 1996). Evidence suggests that individuals with chronic conditions accumulate significant out-of-pocket expenses with health care over time. Among Medicare beneficiaries, a longitudinal survey of their out-of-pocket expenses showed that for those with chronic conditions, out-of-pocket expenditures rose significantly over time (Riley, 2008). Ninety-percent of physicians report awareness of their patients' burden with their out-of-pocket expenses (Alexander, Casalino, & Meltzer, 2005).

Perceptions of financial burden

Measures that assess perceptions of stress or burden 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 of individual environmental demands, their evaluation of events in their life, or their ability to cope (Wright, 2011). Only two studies have similarly operationalized perceived financial burden. In a sample of low-income parents of children with asthma, female heads of household and individuals within the lowest income quartile were more likely to perceive financial burden with their asthma care compared to parents who did not report these perceptions when asked if they feel that their child’s asthma causes financial problems for their family (Patel, Brown, & Clark, 2012(a)). Tseng et al. measured perceptions of financial burden by asking Medicare beneficiaries how difficult it is for them to pay for their prescriptions; 68% reported burden (Tseng et al., 2007). This dissertation will examine perceptions of financial burden using similar measures by asking participants if they consider cost to be a problem with managing their asthma.

The literature conceptualizes financial *barriers* as an inability to access care due to cost (Knoeller, Mazurek, & Mooreman, 2011). In the asthma literature, financial barriers have been operationalized as delaying care due to cost (Knoeller et al., 2011; Nguyen, Zahran, Iqbal, Peng, & Boulay, 2011; Scal, Davern, Ireland, & Park, 2008), which is a behavioral or coping response to a real or perceived financial barrier in terms of access to care (Weissman, Stern, Fielding, & Epstein, 1991), rather than an assessment of an individual’s own appraisal of their ability to afford care despite access.

Ten studies describe financial barriers associated with asthma care (Karaca-Mandic, Jena, Joyce, & Goldman, 2012; Knoeller et al., 2011; Nguyen et al., 2011; Piette, Beard, Rosland, &

McHorney, 2011; Newcomb, McGrath, Covington, Lazarus, & Janson, 2010; Castaldi, Rogers, Safran, & Wilson, 2010; Scal et al., 2008; Piette, Heisler, & Wagner, 2006(a); Rice, Lavarreda, Ponce, & Brown, 2005; Crown et al., 2004). Twenty-percent of adults with asthma report financial barriers with asthma care (Knoeller et al., 2011; Nguyen et al., 2011; Newcomb et al., 2010; Scal et al., 2008). Findings from national data show that individuals with asthma who report financial barriers with their asthma care are more likely to face challenges purchasing medicines or seeing their physician for usual care, have poorly controlled asthma, high out-of-pocket expenses for essential medicines, and experience adverse asthma outcomes including asthma attacks, and urgent care and emergency department visits (Karaca-Mandic et al., 2012; Knoeller et al., 2011; Nguyen et al., 2011; Castaldi et al., 2010). Age differences are evident; young adults with asthma are more likely to report delays and unmet needs in care due to financial barriers compared to adolescents with asthma (Scal et al., 2008).

Other researchers define financial burden as the presence of one of three measures: 1) problems paying medical bills, 2) subjective burden from out-of-pocket expenses, 3) cost-related medication non-adherence within the previous 12 months (Heisler, Wagner, & Piette, 2004; Alexander, Casalino, & Meltzer, 2003). One limitation of this proxy measure of financial burden is that it does not differentiate between perceptions, actual burden as a function of a family’s economic situation, and behavioral responses to cost-related pressures associated with disease management (which includes not following the medical regimen as prescribed by the doctor or delaying and avoiding care).

The majority of studies use quantitative survey data to examine financial burden and/or barriers. Four studies have used qualitative approaches. Semi-structured interviews were used to examine coping strategies with financial burden among 281 low income African American households in the rural South (Strickland & Hanson, 1996). Newcomb et al. identified lack of insurance coverage as a barrier to care for adults with asthma from semi-structured interviews; however, the discussion guide was limited to understanding *barriers* to asthma care and was not specific to financial *burden* (Newcomb et al., 2010). This dissertation will also use qualitative approaches (semi-structured interviews and focus groups) to further examine perceptions of financial burden with asthma care. Such data may provide context for understanding and confirming aspects of asthma care that are perceived financially burdensome.

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. What is known about the relationship between racial discrimination and health outcomes provides a useful analogy for the importance of understanding perceptions of financial burden. Numerous studies document relationships between subjective experiences with unfair treatment and a broad range of mental and physical health outcomes. Social systems organized around racial inequalities (e.g. racially based housing discrimination) also influence health outcomes through pathways that may or may not be subjectively perceived (Schulz et al., 2000). High-income patients have been shown to report cost-related non-adherence to their medical regimen (Piette et al., 2011). Although the majority of adults with asthma have access to care through health insurance, one-third of this group report financial barriers with care (King, 2011). These findings underscore the point that factors beyond economic circumstances and access to care of individuals and families may precipitate perceptions with disease management and subsequently impact patient health. This dissertation will examine what some of those factors may be.

While relationships and pathways exist between financial burden (measured by a behavioral response such as delaying care or non-adherence to a medical regimen) and health outcomes (Karaca-Mandic et al., 2012; Knoeller et al., 2011; Dormuth et al., 2006; Solomon, Goldman, Joyce, & Escarce, 2009; Hunt, Rozenfeld, & Shenolikar, 2009; Dormuth, Neumann, Maclure, Glynn, & Schneeweiss, 2009; Hsu et al., 2006), whether *perceptions* of financial burden also have pathways to health outcomes is unclear. This dissertation complements the existing literature by clarifying the pathways through which patient characteristics influence perceptions of financial burden, and important outcomes of asthma-related urgent care use and self-management behavior come about through solutions that may mitigate burden.

Knowledge about health-related costs

Patients' perception of financial burden and clinicians' ability to foresee and clarify those perceptions is complicated by knowledge of how much patients are paying out-of-pocket for their care. It is also complicated by the variable and wide range of costs associated with health care services, therapies, and health insurance in the U.S. health care system. These costs are often invisible to both patients and clinicians, or they both face barriers in accessing such information. Financial illiteracy in general is widespread and affects two-thirds of the U.S. population (Lusardi, 2008). The elderly and women disproportionately display low levels of financial literacy (Lusardi & Mitchell, 2008). These broader, structural issues manifest at the patient level in health care and affect both health care providers and patients.

Ten studies describe both patient and clinician knowledge about health-related costs (Neumann, Palmer, Nadler, Fang, & Ubel, 2010; Tseng et al., 2009; Benedetti et al., 2008; Khan, Sylvester, Scott, & Pitts, 2008; Schrag & Hanger, 2007; Shrank et al., 2006(a); Shrank et al., 2006(b); Alexander et al., 2005; Ernst et al., 2000; Reichert, Simon, & Halm, 2000). Among physicians, less than 50% report knowing how much their patients spend out-of-pocket for their health care (Khan et al., 2008; Schrag & Hanger, 2007; Shrank et al., 2006 (a); Alexander et al., 2005). Among a sample of internal medicine physicians at one academic medical center, 80% felt unaware of the actual costs of therapies (Reichert et al., 2000). In a sample of family medicine physicians from one state, Ernst and colleagues found that two-thirds of physicians underestimated the actual price of both generic and brand name drugs when asked to select the cash price of commonly prescribed medications (Ernst et al., 2000); in another study, about 40% of sampled physicians overestimated costs (Reichert et al., 2000). Surgeons, emergency department physicians, and physicians who prescribe from more formularies (a list of covered services under a health insurance plan) are less likely to be aware of their patients' out-of-pocket costs (Shrank et al., 2006(a)).

In studies assessing patient knowledge of their out-of-pocket expenses, findings show that about 50-60% of patients are aware of their copayments (Benedetti et al., 2008; Shrank et al., 2006(b)). However, in a study surveying Medicare beneficiaries, Tseng and colleagues found that over 50% did not know their cap levels with their prescription drug benefits (Tseng et al., 2009).

While this dissertation does not examine patients' knowledge of their health-related costs, previous work in this area provides conceptual clarity of the pathways through which perceptions of financial burden and cost of care-related communication affect disease management and health outcomes.

Physician practice patterns based on cost of care to patients

Six studies demonstrate that physicians' change their practice patterns when treating patients whom they perceive as having cost-related concerns with their care (Neumann et al., 2010; Patel, Coffman, Tseng, Cabana, & Clark, 2009; Khan et al., 2008; Pham, Alexander, & O'Malley, 2007; Reichert et al., 2000; Schrag & Hanger, 2007). Findings across studies show that 30-75% of physicians change their prescribing patterns for medication and diagnostic testing in order to reduce financial burden on their patients (Patel et al., 2009; Khan et al., 2008; Pham et al., 2007; Reichert et al., 2000). However, findings are mixed in oncology research. Among a national sample of oncologists, only 16% report omitting treatment options on the basis of their perceptions of patients' ability to afford treatment (Schrag & Hanger, 2007), while among a larger sample of oncologists practicing in one region of the U.S., 84% say that patients' out-of-pocket spending influences treatment recommendations (Neumann et al., 2010).

Differences based on patients' insurance status persist. In a study of primary care physicians treating children with asthma, physicians were less likely to keep costs in mind when prescribing inhaled corticosteroids to their privately insured patients (Patel et al., 2009); other surveys of general internal medicine physicians found that they gave stronger consideration of cost to their self-paying and Medicare patients (Reichert et al., 2000).

This dissertation will not examine physician practice patterns, but findings from the literature suggest that while some physicians are conscious of the costs that patients incur with their care, they may make cost-related adjustments to patients' care and treatment recommendations based on insufficient information and without engaging patients in a discussion as a full partner in determining the trajectory of their care. This dissertation will examine whether patients' perceptions of burden and preferences for communication manifest differently based on their health insurance.

Cost of care-related communication

Patients’ perceptions of financial burden may precipitate preferences for communication with their clinician about the cost of care and available options. The management of chronic disease requires an ongoing partnership over months and years between clinicians and families to actively monitor the therapeutic regimen and adjust the treatment plan to gain optimum control of the condition (Clark et al., 1995). Communication plays an integral role in shaping the relationship between clinicians and patients, and has been shown to affect the process and outcomes of care in asthma (Clark et al., 2008; Diette & Rand, 2007; Roter & Hall, 2006). Discussion about cost of care (cost of care-related communication) between patients and physicians may also influence asthma health outcomes, although the pathways through which this occurs have not been examined. This dissertation will be the first attempt to explore these relationships. The current literature describes barriers, preferences, beliefs and attitudes, initiation, frequency of occurrence, strategies to assist patients, and outcomes as they pertain to cost of care-related communication.

The literature conceptualizes cost of care-related communication as the dialogue in the clinical encounter regarding the direct, out-of-pocket expense of therapeutic recommendations (e.g. medications, devices, environmental modifications, etc.) for the illness management a patient incurs (Benedetti et al., 2008; Shrank et al., 2006(b)). Cost of care-related communication is defined in terms of frequency of occurrence, and also considers whether the patient or physician initiates the dialogue.

Unfortunately, communication about the cost of care occurs infrequently in the clinical encounter (Alexander et al., 2003). Six studies describe barriers that both patients and physicians report with discussing cost of care (Beran, Laouri, Suttorp, & Brook, 2007; Tseng, Buenconsejo-

Lum, Manlucu, & Hixon, 2006; Alexander et al., 2005; Alexander, Casalino, Tseng, McFadden, & Meltzer, 2004(a); Piette, Heisler, & Wagner, 2004(a); Piette, Heisler, & Wagner, 2004(b)). Physicians report common barriers such as discomfort, and perceptions that they can offer their patients no solutions (Beran et al., 2007, Tseng et al., 2006; Alexander et al., 2004(a); Alexander et al., 2005). Barriers reported by patients include discomfort, insufficient time, belief that their physician does not have a solution, their clinician never asked them, feeling embarrassed, and concerns about impact of cost-related discussions on quality of care (Alexander et al., 2004(a); Piette et al., 2004(a); Piette et al., 2004(b)). Although the cost of medical care is not within the control of individual practitioners, addressing patients' cost-related concerns is not always an unsolvable problem. Solutions exist, including switching medicines to a less expensive, but equally effective therapeutic option; stopping nonessential therapies or using them only as needed; taking advantage of governmental and pharmaceutical assistance programs; encouraging patients to shop around for the lowest price on treatment recommendations and reassuring them of equal efficacy of the medicines; prioritizing therapeutic recommendations with the patient; coordinating care with other providers to minimize duplicate services; and facilitating dialogue between patients and support staff to assist with health insurance issues and referring patients to health insurance options (Alexander & Tseng, 2004(b)). In order to offer these solutions to patients, a dialogue with them appears imperative.

Barriers to cost of care-related communication have not been examined among individuals with asthma. Through qualitative in-depth interviews and focus groups, this dissertation will examine barriers to cost of care-related communication from the patient perspective in a population with asthma.

Preferences for cost-related communication

Six studies have documented that both patients and health care providers want to discuss cost in the clinical encounter (Tseng et al., 2010; Donohue, Huskamp, Wilson, & Weissman, 2009; Beran et al., 2007; Tseng et al., 2007; Alexander et al., 2003; Alexander et al., 2004 (a)). Findings show that more than 50% of patients report a desire to talk with their physician about their out-of-pocket medical expenses (Tseng et al., 2010; Donohue et al., 2009; Tseng et al., 2007; Alexander et al., 2003). Patient characteristics that predict this preference are burden of out-of-pocket expenses, difficulty paying for medications, lower income, and poor health (Tseng et al., 2010; Tseng et al., 2007; Alexander et al., 2004(a)).

Both patients and physicians report missed opportunities to discuss the cost of care in the clinical encounter (Tseng et al., 2007; Alexander et al., 2004(a)). Patients who are nonwhite, have low educational attainment, and report high burden of out-of-pocket expenses are more likely to recall a time when they wanted to discuss cost with their provider but did not do so (Alexander et al., 2004(a)). Finding show that more than two-thirds of patients who report no difficulty paying for medications still want their health care providers to ask about affordability, consider cost, and discuss lower cost tradeoffs of therapies and their efficacy (Tseng et al., 2010; Tseng et al., 2007). More than 50% of patients prefer and trust information about drug costs and efficacy their physicians and pharmacists provide relative to other health care providers in a care team (Donohue et al., 2009).

Preferences for cost of care-related communication have not been examined among individuals with asthma or how these preferences come about from patients' characteristics. This dissertation will examine preferences for cost of care-related communication by asking participants how important it is to them discuss the cost of their asthma care with their health care provider, and examining pathways through which patient characteristics manifest to preferences through economic mediators. Qualitative, supporting information will be extracted through focus groups.

Beliefs and attitudes about cost of care-related communication

Nine studies have examined beliefs and attitudes about cost of care-related communication from perspectives of both the patient and health care provider (Donohue et al., 2009; Khan et al., 2008; Benedetti et al., 2008; Schrag & Hanger, 2007; Shrank et al., 2006(a); Shrank et al., 2006(b); Tseng et al., 2006; Alexander et al., 2005; Alexander et al., 2003). Findings show that more than 80% of health care providers consistently recognize their obligation to discuss and consider patients' out-of-pocket expenses when writing or renewing prescriptions or recommending therapies (Khan et al., 2008; Schrag & Hanger, 2007; Shrank et al., 2006(a); Tseng et al., 2006; Alexander et al., 2005). About 80% of physicians believe that their patients want to discuss their out-of-pocket expenses (Alexander et al., 2003), which is consistent with patient preferences (Tseng et al., 2010; Donohue et al., 2009; Tseng et al., 2007; Alexander et al., 2003). Some providers believe it is not their responsibility to address patients' cost-related concerns. One study showed that while 90% of physicians agreed that it is important to discuss patients' out-of-pocket expenses, 65% believed that it is the responsibility of the pharmacist to be familiar with patients' out-of-pocket costs (Shrank et al., 2006(a)). Further, in a random sample of California physicians, a self-report survey of physicians' perceptions of prescription drug costs and the importance of communication found that over 80% of physicians agreed that it is important to minimize out-of-pocket expenses, but only 23% of physicians saw the value of a discussion about these expenses with their patients (Shrank et al., 2006(b)).

Findings from a sample of deductible plan enrollees from a large employer surveyed about their copayments and care seeking behavior showed that 79% of patients believe that their providers cannot help them with their expenses and 51% believe that it is inappropriate to discuss costs with the their physician (Benedetti et al., 2008).

Existing studies on beliefs concerning cost of care-related communication have primarily been undertaken in general clinical populations. Some providers and patients believe that cost of care-related discussions are important, while others do not share these beliefs. Beliefs and attitudes about cost of care-related communication have not been examined exclusively among individuals with chronic diseases. This dissertation will examine beliefs and attitudes about cost of care-related communication through focus groups among individuals with asthma.

Frequency of cost-related communication

Seventeen studies have examined how often cost of care-related communication occurs in the clinical encounter. Findings consistently show that this discussion occurs infrequently and less than 50% of the time as reported by patients (13 studies), health care providers (eight studies), and objective observation (one study) (Beard et al., 2010; Neumann et al., 2010; Newcomb et al., 2010; Tseng et al., 2010; Patel et al., 2009; Tseng et al., 2009; Benedetti et al., 2008; Wilson et al., 2007; Tseng et al., 2007; Beran et al., 2007; Shrank et al., 2006(a); Shrank et al., 2006(b); Tarn, Paterniti, Heritage, Hays, Kravitz, & Wenger, 2006; Heisler et al., 2004; Piette et al., 2004(a); Piette et al., 2004(b); Alexander et al., 2003).

In a sample of over 1,000 Medicare beneficiaries, patient self-report found that although over 90% of health care providers chose medications for patients, less than 50% offered choices and less than 20% inquired about affordability or discussed prices (Tseng et al., 2007). In a cohort study of 104 adults with asthma, qualitative data from semi-structured interviews showed that they rarely reported problems obtaining medications and those associated with miscommunication between the health care provider and pharmacy (Newcomb et al., 2010).

Cost of care-related communication is more likely to occur with patients who have low income, low educational attainment, are burdened by out-of-pocket expenses, seen in community practice, no pharmacy benefits or benefits requiring co-payments, cutting back on medications, as well as white patients and physicians, and with physicians with high perceived knowledge of costs. (Beard et al., 2010; Beran et al., 2007; Tarn et al., 2006; Shrank et al., 2006(a); Heisler et al., 2004; Piette et al., 2004(a); Alexander et al., 2003).

In a large national sample of adults aged 50 years and older who were taking medication for one of five common chronic conditions, Heisler and colleagues found that independent of financial burden, African American patients, patients taking seven or more medications, and patients without pharmacy health insurance benefits experienced a greater likelihood of being asked about cost problems by their health care provider (Heisler et al., 2004).

Frequency of cost of care-related communication has not been examined among individuals with asthma. This dissertation will examine frequency of cost of care-related communication by asking participants how often they discuss the cost of their asthma care with their health care provider. In-depth information will be extracted through focus groups.

Initiation of cost of care-related communication

Four studies describe who initiates cost of care-related communication in the clinical encounter (e.g. the patient or the health care provider) (Beard et al., 2010; Beran et al., 2007; Tseng et al., 2007; Tarn et al., 2006). Two studies found that more patients than physicians self-reported initiating cost of care-related discussion within samples of older adults (Beran et al., 2007; Tseng et al., 2007). However, in studies of coded audio-taped clinical visits, Beard and colleagues found that patients initiated 48% of cost-related discussions (Beard et al., 2010). Tarn et al. found that even fewer patients (2%) initiated related conversations (Tarn et al., 2006).

From the patient perspective, cost of care-related communication has been measured through self-report surveys, and two studies audio-recorded clinic visits between provider and patient (Beard et al., 2010; Tarn et al., 2006). Self-report measures demonstrate high face and content validity, and consistent findings across studies (Beard et al., 2010; Benedetti et al., 2008).

Cost of care-related communication has not been examined among individuals with asthma. This dissertation will examine preferences, initiation, and frequency of occurrence of cost of care-related communication through self-report survey data from patients.

Strategies used to help patients with costs

Six studies have described specific strategies healthcare providers recommend and use to assist their patients with cost of care-related concerns (Donley & Danis, 2011; Gellad, Huskamp, Li, Zhang, Safran, & Donohue, 2011; Alexander et al., 2005; Beran et al., 2007; Hardee, Platt, & Kasper, 2005; Alexander & Tseng, 2004(b)). Alexander and colleague have described six practical strategies that health care providers can apply to assist their patients burdened by their out-of-pocket costs, including switching to a less expensive but equally effective medication, stopping nonessential medicines or using them only as needed, splitting pills, using office samples, taking advantage of governmental and private pharmaceutical assistance programs, and encouraging patients to shop around for the lowest price (Alexander & Tseng, 2004(b)). Others have described techniques on empathetic communication for providers in assisting their patients with cost-related concerns (Donley & Danis, 2011; Hardee et al., 2005). The most common strategies that health care providers report using include switching to a generic drug, using office samples, and discontinuing nonessential medicines (Beran et al., 2007; Alexander et al., 2005).

No studies have examined the utility of strategies from the patient's perspective. This dissertation will fill this gap in the literature by asking patients what options have been offered to them that have proven helpful. This information will be extracted through focus groups.

Outcomes of cost of care-related communication

Eight studies report proximal outcomes associated with cost of care-related communication in the clinical encounter (Gellad et al., 2011; Beard et al., 2010; Wilson et al., 2007; Schrag & Hanger, 2007; Shrank et al., 2006(a); Piette et al., 2004(a); Piette et al., 2004(b); Korn, Reichert, Simon, & Halm, 2003). Key outcomes associated with cost of care-related communication include receiving samples, stopping nonessential medicines, switching from brand name to generic medicines, receiving information about financial assistance programs, and referral to support staff (Gellad et al., 2011; Beard et al., 2010; Wilson et al., 2007; Schrag & Hanger, 2007; Piette et al., 2004(a)). However, across studies, a positive outcome from cost of care-related communication only occurred in less than 60% of patient encounters (Beard et al., 2010; Piette et al., 2004(a)). In a national sample of Medicare beneficiaries, 50% of seniors received free samples of prescriptions, but higher income individuals were more likely to receive these samples than low income individuals. Only about 1% of seniors reported receiving referrals to pharmaceutical assistance programs (Gellad et al., 2011), suggesting that alternative options to assist patients with cost-related concerns are severely underutilized. Thirty-percent of patients report not receiving a medication change or referral to a pharmaceutical assistance program even after conversing with their health care provider about their medication costs (Piette et al., 2004(b)).

Productive communication appears to ameliorate patient perceptions and concerns. More than a dozen studies show a positive and significant relationship between aspects of communication and patients’ health outcomes, including recovery from emotional problems, improved physiologic and functional status, and symptom resolution (Frankel, Quill, & McDaniel, 2003). In pediatric asthma, randomized control trials have shown that patients’ disease management can be facilitated by effective communication in the clinical encounter. Physicians who participated in a communication intervention inquired about patients' concerns, and provided clear and concise asthma education relative to control physicians; their patients had fewer days with symptoms, emergency department visits and hospitalizations (Cabana et al., 2006; Clark et al., 1998). Communication specifically about the cost of care between patients and health care providers may similarly influence patient health outcomes, and this dissertation will fill a gap in the literature by beginning to explore this relationship.

Numerous studies show high correlation with collaboration and communication between patients and health care providers, and patients’ ability to self-manage their chronic condition (National Asthma Education and Prevention Program [NAEPP], 2007; Rubin, Peyrot, & Siminerio, 2006). Patient-reported self-management behaviors are meaningful outcomes in health care interventions, as they are associated with critical long-term outcomes that may otherwise prove difficult to measure: functional capacity, complications, mortality, health care costs, and quality of life (Rand et al., 2012). Self-management behaviors as an outcome in this study will provide insights into the utility of cost of care-related communication when adjusted for other factors that affect disease management.

This dissertation will also examine urgent care use for asthma as an outcome. The need for urgent treatment for asthma often reflects inadequate maintenance therapy and insufficient knowledge of how to address worsening of asthma control (Lazarus, 2010).

Theories and Frameworks

To date, a theory or conceptual framework has not been used to guide empirical investigations of influences and outcomes of cost of care-related communication between the patient and health care provider. Piette and colleagues describe a conceptual framework to better understand how patient, medication, clinician, and health system factors influence *behavioral responses* to cost-pressures by patients (Piette, Heisler, Horne, & Alexander, 2006(b)). The framework suggests that both the complexity of the therapeutic regimen and financial pressures are directly related to cost-related non-adherence to prescribed therapies. Contextual factors modify the cost-adherence relationship, including patients' characteristics (e.g. age, ethnicity, and attitudes toward medications), the type of medication they use (e.g. drug's clinical target), clinician factors (e.g. choice of first-line agent and communication about medication costs), and health system factors (e.g. efforts to influence clinicians' prescribing and to help patients apply for financial assistance programs) (Piette et al., 2006(b)). This framework is limited in that it is specific to prescription medication only, neglects the role of the patient as an active partner in communication about the cost of care and formulation of the treatment plan, and omits pathways to health outcomes. The framework also assumes that behavioral responses to cost-pressures occur as a result of actual economic and access to care-related factors and does not consider the pathways of patient perceptions of their own situations and circumstances and subsequent influences on complying with a treatment plan. This dissertation will present a conceptual framework of factors and influences of cost of care-related communication, and formally test these pathways from the patient perspective. A key mediator in the proposed model is perception of financial burden with asthma management: an individual's own appraisal of their financial situation as it concerns chronic disease management.

Samples in Existing Studies

Thirty six studies have examined financial burden of medical care and cost of care-related communication from the patient perspective. Eleven studies have derived their samples from a clinic population, 15 used national survey samples, and seven studies retrieved samples from insurance claims databases. From the patient perspective, 13 studies have investigated financial burden and cost of care-related communication in specific chronic disease populations. Seven studies have looked at only individuals with chronic respiratory diseases/asthma (Karaca-Mandic et al., 2012; Patel et al., 2012(a); Nguyen et al., 2011; Castaldi et al., 2010; Newcomb et al., 2010; Knoeller et al., 2008; Scal et al., 2008), and four studies considered individuals with cancer (Bernard et al., 2011; Pisu, Azuero, McNees, Burkhardt, Benz, & Meneses, 2010; Moore, 1998; Given, Given, & Stommel, 1994). Diabetes (Piette, Heisler, Krein, & Kerr, 2005; Piette et al., 2004(b)) and rheumatoid arthritis (Beard et al., 2010) have also been examined. Seven studies have included the adult population, individuals 18 and older (Nguyen et al., 2011; Knoeller et al., 2011; Tseng et al., 2010; Benedetti et al., 2008; Tarn et al., 2006; Alexander et al., 2004(a); Alexander et al., 2003), while 16 studies have included samples of select age cut-offs (Piette et al., 2011; Bernard, et al., 2011; Beard et al., 2010; Newcomb et al., 2010; Pisu et al., 2010; Donohue et al., 2009; Scal et al., 2008; Shrank et al., 2006(a); Shrank et al., 2006(b); Banthin & Bernard, 2006; Piette et al., 2006(a); Sharkey, Ory, & Browne, 2005; Rice et al., 2005; Heisler et al., 2004; Piette et al., 2004(a); Piette et al., 2004(b)), and seven studies have only looked at individuals 65 years of age and older (Gellad et al., 2011; Castaldi et al., 2010; Tseng et al., 2009; Riley et al., 2008; Tseng et al., 2007; Wilson et al., 2007; Stewart, 2004).

A limitation that arises from samples in these studies concerns generalizability of findings, specifically as they pertain to racial/ethnic minority groups. Only two studies have recruited samples with a heterogeneous racial/ethnic composition of participants, while 26 studies have samples in which 70% of participants self-report their race/ethnicity as white (Gellad et al., 2011; Piette et al., 2011; Bernard et al., 2011; Nguyen et al., 2011; Knoeller et al., 201l; Newcomb et al., 2010; Beard et al., 2010; Castaldi et al., 2010; Donohue et al., 2009; Tseng et al., 2009; Benedetti et al., 2008; Scal et al., 2008; Tseng et al., 2007; Wilson et al., 2007; Piette et al., 2006(a); Banthin & Bernard, 2006; Shrank et al., 2006(a); Tarn et al., 2006; Rice et al., 2005; Sharkey et al., 2005; Piette et al., 2005; Heisler et al., 2004; Piette et al., 2004(a); Piette et al., 2004(b); Stewart, 2004). No studies that have examined perceptions of financial burden and cost-related communication exclusively among racial/ethnic minority groups. Such groups are most vulnerable to economic, access to care, and quality of care-related challenges.

African American Women with Asthma

There is reason to believe African American women with asthma comprise a sub-group at particularly high risk of experiencing perceptions of financial burden. Asthma prevalence based on current physician diagnosis is highest among African American women (Centers for Disease Control and Prevention, 2011). Among these women, respiratory diseases rank among the ten leading causes of death (Akinbami, Mooreman, Liu, 2011; LaVeist, 2005). African Americans report more multimorbidity with asthma and have three times the rate of emergency department visits, hospitalizations, and deaths attributable to asthma compared to whites (Akinbami, et al. 2011).

Several environmental and structural factors may indirectly put African Americans at greater risk for asthma and perception of financial burden with its management. Living in urban inner city environments, where a large proportion of African Americans reside, has been identified as a risk factor for asthma prevalence, in addition to poverty, low socioeconomic position and less access to primary care (von Maffei et al., 2001; LaVeist, 2005). Inner-city environments are often characterized by overcrowding and dilapidated housing, which become hot spots for asthma allergens (Bryant-Stephens, 2009). Higher concentrations of African Americans live in inner city, urban environments due to a long history of residential segregation and discrimination (Alex-Assensoh & Assensoh, 2001), which increase their asthma-related risk exposures and leads to disproportionate rates of asthma morbidity and mortality (Ford & McCaffrey, 2006). Further, individuals living in areas where they have less access to quality medical care may incur higher out-of-pocket and opportunity costs due to the travel time and lost work time required to reach more resource abundant areas, which may in turn influence both perceptions and actual financial burden associated with asthma management.

Upwardly mobile African American women may also be at risk for perceptions of financial burden with asthma management due to racial and gender disparities in economic opportunities that persist within this population. In the U.S, trends suggest that women still have lower earning potential than males (Blau & Kahn, 2003), disproportionately represent single parent households (Blackwell, 2010), and are also the primary care takers of chronically ill children, which may reduce their earning potential (Hobbs, Perrin & Ireys, 1985). In addition, research shows that racial/ethnic background may directly influence household income due to historical consequences of differential access to economic resources and earning potential (Williams & Collins, 2002). Compared to non-Hispanic white women, African American women are more likely to be the primary wage earners in their families; remain the most underrepresented subgroup in private sector professional jobs; earn lower wages at each educational level and realize less of a payoff for additional education. They are twice as likely to give support resources to family and friends than they are to receive them; receive lower economic benefits from marriage, and face lower rates of marriage and higher rates of marital dissolution due to both the social and economic conditions that continue to persist for some predominately African American communities because of high rates of incarceration among African American males (Jackson & Williams, 2006).

African American women may also be especially vulnerable to communication challenges in the clinical encounter. Physicians have been shown to be less patient-centered in their communication approach with African American patients compared to non-Hispanic white patients (Cooper & Roter, 2003; Cooper-Patrick et al., 1999). Demographic disparities in general communication between patients and physicians appear to result in differential health outcomes including satisfaction with care, physiologic indicators, and compliance with medical recommendations (Cooper & Roter, 2003; Roter & Hall, 2006).

The simultaneous exposure of greater burden of lung disease, socioeconomic disparities, and deficiencies in communication in the clinical encounter may put African American women at a greater risk for difficulties with self-management and concomitantly, perception of greater financial burden related to managing asthma. African American women thus comprise a unique population for examining the most difficult cases in which influences of communication with a health care provider are most likely to determine key outcomes. The sample for this dissertation is not representative of all individuals or even women with asthma, but does represent those with the poorest outcomes.

Even within a group of African American women, there may be considerable variation in terms of factors that influence perceptions of financial burden, preferences for cost of care-related communication with health care providers, and the influence of these discussions on their health outcomes. Examining these relationships among a sub-population at high risk for perceptions of financial burden may elucidate patient and disease factors above and beyond the racial/ethnic background of patients in explaining pathways through which they perceive financial burden and how cost of care-related communication between clinicians and patients influences health outcomes.

Lastly, little is known about the unique characteristics related to cost of care-related communication among individuals with asthma, which is another gap this dissertation will fill. This is important to understand because chronic conditions vary widely in the management strategies and therapies required and the frequency in which one may need to interface with the health care system to guide self-management. Further, understanding perceptions of financial burden relative to specific chronic conditions may help clinicians to better target productive communication with their patients.

Methodology

All studies to date have examined direct relationships between patient characteristics that predict financial burden and cost of care-related communication using multivariate regression statistical techniques (Hofstatter, 2010). A methodological gap in the current literature is that no studies have explicitly examined the pathways through which perceptions of financial burden and preferences for cost of care-related communication occur. Also, no studies have examined the pathways through which cost of care-related communication is associated with patient health outcomes. Perceptions of financial burden may be influenced by patients' economic, demographic and disease characteristics, which may in turn influence patients' preferences and/or whether they actually discuss the cost of their care with their physician. Failing to identify pathways through which these perceptions occur may deny health care providers sufficient information to correctly identify patients who may require more support to effectively self-manage their condition, and may adversely impact the patient-clinician relationship. This dissertation will explore these indirect relationships using path analysis.

Summary

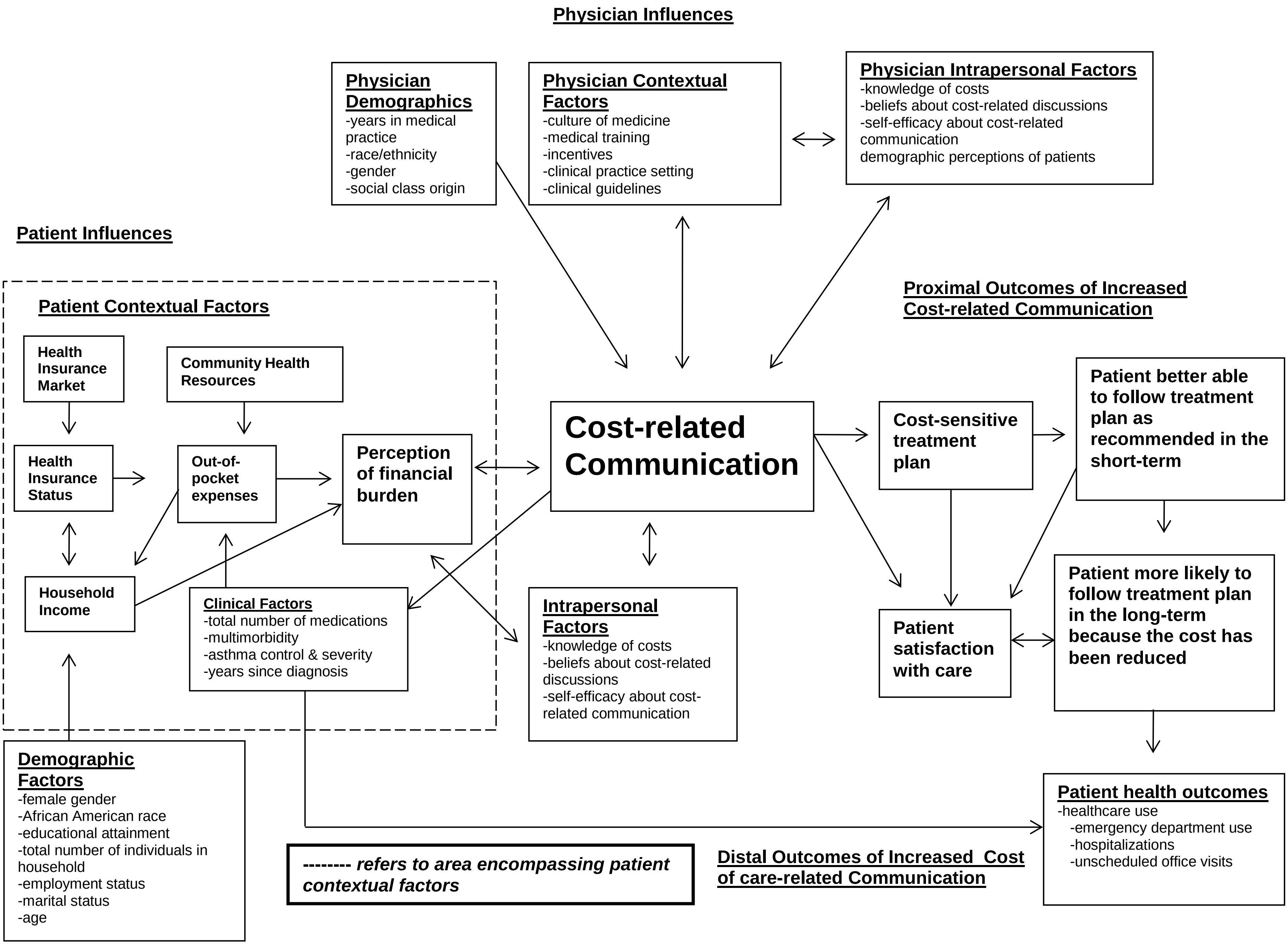
Several conceptualizations of financial burden exist in the literature. These conceptualizations are based on the objective financial circumstance of individuals and families, their subjective experience, and as a function of their behavioral response to cost-related concerns. When financial pressures arise, patients have been shown to delay care and not comply with therapeutic regimens. Although both patients and health care providers would like to discuss the cost of care, these discussions occur infrequently. The literature describes several patient and disease factors that predict financial burden and cost of care-related communication. To date, a framework has not been devised that outlines relationships between *perceptions* of financial burden, cost of care-related communication, and health outcomes and considers the influence of both the health care provider and patient in shaping communication. No studies have explored the pathways through which economic, demographic, and clinical characteristics influence patients' perceptions of burden and preferences for cost of care-related communication with their health care provider. The pathway through which cost of care-related communication influences health outcomes has also not been explored. These relationships have not been explored exclusively among vulnerable populations who face a disproportionate burden of disease in society. This dissertation fills a gap in the literature by describing a conceptual framework of factors and influences of cost of care-related communication among women with asthma, and formally testing these pathways from the patient perspective within this framework.

Conceptual Model of the Influences and Outcomes of Cost of Care-Related Communication between Physicians and Women with Asthma

This dissertation is based on a model of cost of care-related communication in the clinical encounter and important asthma outcomes (see Figure 2.1).

The conceptual model describes influences and outcomes of cost of care-related communication between physicians and patients, specifically women with asthma. Patient contextual factors (health insurance status, health insurance market, clinical factors, community health resources, out-of-pocket expenses, household income) and patient demographic factors (educational attainment, African American race, female gender, number of individuals in the household, marital and employment status, age) moderate patient perception of financial burden in complex ways. Perceptions of financial burden subsequently mediate the relationship between patient contextual factors and cost of care-related communication. Patient intrapersonal factors (knowledge of costs, beliefs and self-efficacy concerning cost-related communication) may also influence cost of care-related communication. The conceptual model posits that physician contextual factors (culture of medicine, medical training, incentives, clinical practice setting, clinical guidelines), intrapersonal factors (knowledge of costs, beliefs and self-efficacy concerning cost of care-related communication, demographic perceptions of patients), and demographic factors (years in medical practice, race/ethnicity, gender, social class origin) all influence physicians’ perspective of cost of care-related communication in the clinical encounter.

Figure 2.1: Conceptual model of cost of care-related communication between physicians and women with asthma: influences and outcomes.



Cost of care-related communication between the physician and patient may subsequently lead to proximal outcomes (patient satisfaction with care), or the patient following the recommended treatment plan in the short-term when mediated through the development of a cost-sensitive treatment plan. Following the treatment plan in the long-term mediates the relationship between following the treatment plan in the short-term, patient satisfaction with care, and distal outcomes of improved patient health outcomes through reduced urgent care use (emergency department visits, hospitalizations, and unscheduled office visits).

Theoretical Rationale

Constructs and principles drawn from the Behavioral Model of Health Services Use and social cognitive theory guide the conceptual model in this dissertation (Baranowski, Perry, & Parcel, 2002; Anderson, 1995). The Behavioral Model of Health Services Use posits that people’s use of health services is a function of their predisposition to use services (intrapersonal and demographic factors), factors which facilitate or impede use (household income, health insurance coverage, community health resources), and their need for care (clinical factors). In the conceptual model, the primary outcome is urgent care use, which is an undesirable outcome that enabling factors should reduce. Both community, health care system and personal enabling resources (patient and physician factors) must be present for use to occur, and health beliefs, values, and knowledge that people have about health and health services might influence their subsequent perceptions of need, care-seeking, and use of health services (perception of financial burden with care). Perceptions are largely explained by both social factors and intrapersonal factors. Social relationships can serve as an enabling resource to facilitate or impede health services’ use and compliance with a medical regimen (cost of care-related communication in the clinical encounter between the patient and physician).

Constructs from social cognitive theory that guide the proposed model include reciprocal determinism, outcome expectations, and self-efficacy. Social cognitive theory posits that human behavior is explained through a dynamic, reciprocal interplay of personal, behavioral, and environmental influences, and that individuals have the potential to alter and construct their environments to suit purposes they devise for themselves (Bandura, 1997). Self-efficacy concerns people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives, which can determine how people feel, think, motivate themselves and behave (Bandura, 1997). Patients and physicians may influence each other in a reciprocal dynamic through information exchange in the clinical encounter (Cooper & Roter, 2003). A person learns that certain events are likely to occur in response to their behavior in a particular situation (Baranowski et al., 2002). Perceptions of financial burden may lead one to expect inability to perform self-management tasks. The immediate outcome expectation in the proposed model is a cost-sensitive treatment plan that results from communication between physician and patient and facilitates self-management.

Conceptual Model Assumptions

The model assumes that the prescribed therapeutic regimen for the patient is the right one for her and the physician continues to recommend it. It is also assumed that since the therapeutic regimen is for the treatment of a specific condition (asthma), changes to the treatment plan will be asthma-specific. Several other factors are known to affect compliance with a treatment plan, including side-effects from medications, literacy, forgetfulness, and effectiveness of medicine from the patient’s view (Jin, Sklar, Oh, & Chuen, 2008). This conceptual model is only focused on understanding perceptions associated with cost-related factors and their contribution to explaining health outcomes in women with asthma.

Key Factor

Cost of care-related communication

Cost of care-related communication is central to the model and the behavior of interest. It comprises dialogue in the clinical encounter surrounding the direct, out-of-pocket expenses of therapeutic recommendations (e.g. medications, devices, environmental modifications, etc.) for illness management, which may also include indirect costs (e.g. lost work time) a patient incurs via their asthma management. Cost of care-related communication encompasses frequency of occurrence, whether the patient or physician initiates the dialogue, and patient preferences for such discussions.

Patient Contextual Factors

Perception of financial burden

This model defines perception of financial burden as the subjective financial strain the patient experiences due to asthma management; it is based on a self-appraisal of their own situation. Patients who report financial burden are more likely to discuss costs with their physician (Alexander et al., 2003).

Out-of-pocket expenses

Out-of-pocket expenses are conceptualized in the literature as residual costs to the patient that health insurance or health systems do not pay (Hobbs et al., 1985). This model includes copayments and deductibles. Out-of-pocket expenses may reduce household income, since some health insurance plans have deductibles and spend-down policies, whereby patients spend their income out-of-pocket before insurance covers medical expenses (Centers for Medicare and Medicaid Services, 2011). Out-of-pocket expenses may also influence patient perception of financial burden, as national data show that those who spend more of their income out-of-pocket on medical care are more likely to be burdened by these expenses (Banthin & Bernard, 2006).

Community health resources

Community health resources are defined in terms of the availability of health resources in a given region. It also includes geographic variation in health spending. In this model, both conceptualizations may influence cost-related communication through patients' out-of-pocket expenses and perceptions of financial burden. The availability of quality medical care in low-income, urban areas, where asthma prevalence has been shown to be highest, is frequently lacking (Cloutier, Wakefield, Hall, & Bailit, 2002). Primary care physicians, who often diagnose and treat asthma, tend to locate in higher income areas due to lack of incentive to provide care in predominately low-income neighborhoods where many individuals are covered under Medicaid (Fossett, Perloff, Peterson, & Kletke, 1990). Medicaid provides the lowest levels of reimbursement to physicians, and areas with high concentrations of Medicaid patients have historically dealt with inadequate physician supply (Fossett et al., 1990).

Community health resources also contribute to geographic variation in health care spending. Decades of research have shown that areas with more physician supply, technology, and hospital beds have far more medical resource utilization than areas with less supply, but similar patient populations and rates of disease burden (Wennberg, 2010). Due to high spending per capita in regions that utilize more medical care, patients in these areas face higher insurance copayments (Dartmouth Atlas of Healthcare, 2008). Patients in high spending areas are also more likely to receive more invasive and expensive procedures, and fall into systems with high coordination deficits in delivery compared to low spending areas (Song et al., 2010; Baicker & Chandra, 2008). Additionally, regions with high rates of uninsured individuals have been shown to intensify financial pressures on local health care delivery systems by decreasing medical resources and posing difficulties for insured individuals to obtain needed care (Institute of Medicine, 2009). All of these factors contribute to increasing out-of-pocket costs to patients and potentially influencing perceptions of financial burden.

Patient clinical factors

Several patient clinical factors (including total number of medications, multimorbidity, years since initial asthma diagnosis, frequency of symptoms, and asthma control) may influence patient perception of financial burden, mediated through out-of-pocket expenses. In the model, total number of medications refers to the number of therapeutic strategies recommended to effectively manage whatever chronic conditions a patient has. The literature conceptualizes total number of medications as the total number of prescriptions one is prescribed at any given time (Donohue et al., 2009). The complexity in an asthma management regimen may lead to out-of-pocket expenses and perceptions of financial burden; prescription drugs, medical equipment and visual aids account for the majority of out-of-pocket expenses for individuals with chronic conditions, but prescription drug costs demonstrate the highest expense (Hwang, Weller, Ireys, & Anderson, 2001).

Multimorbidity refers to the number of chronic conditions that an individual is managing in addition to asthma. Managing multiple chronic conditions may lead to perceptions of financial burden, since increasing number of conditions has been shown to be directly correlated with increasing out-of-pocket expenses (Paez, Zhao, & Hwang, 2009). Cost of care-related communication is also more likely to occur among patients with multimorbidity (Alexander et al., 2003).

In this model and in clinical asthma care, the NAEPP Guidelines for the Diagnosis and Management of Asthma conceptualize frequency of asthma symptoms based on intensity of disease process, and asthma control as the current impairment and future risk after therapy has been initiated (NAEPP, 2007). Frequency of symptoms and control of a chronic condition may influence patient perceptions of financial burden through out-of-pocket expenses; adults with less well-controlled and more frequent asthma symptoms have direct and indirect costs of care that are significantly higher than more controlled and milder forms of asthma (Accordini et al., 2006; Serra-Batlles, Plaza, Morejon, Comella, & Brugues, 1998). Although associations between asthma control, frequency of symptoms, and years since initial asthma diagnosis and cost of care-related communication have not been well described, it is possible that perceptions of financial burden at varying levels of illness history may influence the initiation and frequency of cost of care-related discussions with health care providers.

Health insurance market

The U.S. health insurance market may indirectly influence perception of financial burden and subsequent cost of care-related communication. Economic concepts underlie the conceptualization of the health insurance market because transactions occur between buyers and multiple sellers in the U.S. for the purchase and/or acquisition of health insurance (Folland, Goodman, & Stano, 2010). This includes government-sponsored insurance, which the private market often administers in order to contain costs and generate efficiencies (Folland et al., 2010). The state of the health insurance market prior to the passage of the 2010 Patient Protection and Affordable Act (PPACA) and subsequent health insurance expansions still remains at the time of this writing, except for adult dependent coverage. Adult dependent coverage up to age 26 went into effect on September 23, 2010, and has since expanded health insurance coverage to 3 million young adults (U.S. Department of Health and Human Services, 2012(a); Kaiser Family Foundation, 2011).

The purpose of health insurance based on economic and actuarial principles is for individuals to transfer the risk of considerable financial loss from an illness episode to an insurer through a small premium (Folland et al., 2010). Insurance companies charge individuals more for health insurance than their anticipated medical costs; these extra costs vary based on the risk profile of the entire insurer pool and administrative expenses that insurance companies incur. In the U.S., health insurance was initially designed to provide financial coverage for select services for acute illness rather than the broad range of long-term services needed for chronic illness.

The top health care systems in the world all guarantee health insurance to their citizens and employ federal committees that set price regulations, negotiate contracts with the private sector, and institute strict policies with payers to control rising health care costs (Anderson & Frogner, 2008). In the U.S., two-thirds of the population receives health insurance through a minimally regulated private market in which most insurance companies are for-profit (Kaiser Commission on Medicaid and Uninsured, 2010). As a result, the U.S. pays higher prices for the same pharmaceuticals and medical technology than other developed countries, and these costs impact health insurance rates for individuals and their subsequent out-of-pocket costs (Anderson, Reinhardt, Hussey, & Petrosyan, 2005). Historically, the U.S. has not guaranteed access to affordable health insurance as a fundamental right. The economic forces that drive the health insurance market may influence a patient’s health insurance status with respect to having insurance, the kind of insurance available to them, and their out-of-pocket expenses.

Patient health insurance status

Health insurance status in the model refers to the type of health insurance a patient is covered under (e.g. private, state-sponsored, government sponsored, etc.). Health insurance status may impose varying levels of protection against individual financial risk. Among the nation’s insured adults (81%), 62% are covered under private health plans, and 20% are covered under public insurance programs such as Medicare and Medicaid (Kaiser Commission on Medicaid and Uninsured, 2010).

Both private and public insurance plans have varying levels of cost-sharing within their benefit designs (Artiga & O’Malley, 2005). In response to containing rising health care costs in the private insurance market, employers and insurers have been shifting more responsibility of costs to the insured through higher premiums, higher deductibles, higher copayments, and reduced benefits (Galvin & Delbanco, 2006; Gabel et al., 2003). The degree of cost-sharing at the point of care associated with plans is often based on the cost efficiency of the choice of plan (Goff, 2004). Employer-sponsored private insurance dominates the U.S. health insurance market, with over 60% of the nonelderly population covered through their employer in 2007, representing 90.1% of all private coverage (Fronstin, 2007). Benefits are paid in large part out the wages of employees, and when costs of benefits rise, wages have been shown to fall or rise more slowly (as cited in Baicker & Chandra 2008). In the pediatric literature, some evidence suggests that public health insurance provides better financial protection than private insurance for families with special health care needs (Yu, Dick, & Szilagyi, 2008).

Americans without access to employer-sponsored health coverage or who do not meet requirements for government-sponsored insurance must turn to the non-group health insurance market for coverage. For many people, non-group coverage is prohibitively expensive or altogether unavailable; in many states insurers may deny applicants for non-group coverage completely, impose either a permanent or temporary preexisting condition limitation on coverage, or charge a higher premium based on health status, occupation, and other personal characteristics (Institute of Medicine, 2009).

Medicare is a federally sponsored health insurance program for adults 65 years in age and older regardless of income or medical history, and individuals under 65 years of age with permanent disabilities. Half of all people on Medicare have incomes below $22,000, less than $53,000 in savings, and three or more chronic conditions (Kaiser Family Foundation, 2012). Medicare has relatively high deductibles and cost-sharing requirements; many beneficiaries also have either supplemental, private insurance coverage called Medigap or supplemental coverage that they receive through employer-sponsored plans or purchase directly through the private insurance market in order to cover out-of-pocket expenses. In 2010, 20% of Medicare beneficiaries had supplemental coverage through the private market (Kaiser Family Foundation, 2012). For low-income Medicare beneficiaries, Medicaid provides supplemental coverage, and 21% of beneficiaries use this option (Kaiser Family Foundation, 2012). The Medicare Advantage Program, which provides coverage to 25% of Medicare beneficiaries, is a private market program that provides first dollar coverage of Medicare-covered benefits without a deductible (Kaiser Family Foundation, 2012). Eleven-percent of Medicare beneficiaries have no supplemental coverage, and they are more likely to be the under-65 disabled, the near poor (incomes between $10,000 and $20,000), rural residents, or African American (Kaiser Family Foundation, 2012).

Medicaid is a federally sponsored program administered by individual states to provide health insurance coverage for low-income families and elderly, and individuals with disabilities.

As previously mentioned, for low-income elderly, Medicaid serves the purpose of supplemental health insurance for Medicare and provides coverage for 20% of their beneficiaries. Due to rising costs to states of sustaining Medicaid programs, the Deficit Reduction Act of 2005 allowed states to begin charging nominal co-pays and premiums to Medicaid recipients. Certain groups (children, pregnant women, and individuals in hospice) are exempt from cost-sharing. While states can charge beneficiaries based on family income, cost-sharing charges cannot exceed 5% of their income (U.S. Department of Health and Human Services, 2008).

Other health coverage in the U.S. includes military benefits, the Indian Health Service and state-sponsored plans. The military health system provides health insurance coverage to all active duty and retired U.S. military personnel and their dependents. Benefit designs vary in terms of deductible requirements, enrollment fees for retirees and family members, and fees to see civilian providers (Military.com, 2012). The Indian Health Service is not an insurance program and does not have an established benefits package (U.S. Department of Health and Human Services, 2012(b)). Funds appropriated by the U.S. Congress to support Indian Health Service facilities currently cover an estimated 60% of health care needs of the eligible American Indian and Alaska Native people (U.S. Department of Health and Human Services, 2012(b)). State-sponsored plans are available for low-income individuals who do not qualify for public insurance programs or do not have access to affordable coverage (Healthinsurance.org, 2012).

A patient’s health insurance status may impose varying levels of out-of-pocket expenses, and may influence perception of financial burden and cost of care-related communication. Even minimal levels of cost-sharing can be burdensome to low-income families covered through Medicaid (Selden, Kenney, Pantell, & Ruhter, 2009), and cost concerns are more often mentioned by individuals with private health insurance or no coverage (Devoe et al., 2007;

Shrank et al., 2006(b)). Employer-sponsored insurance may also increase perceptions of financial burden for patients in the form of lower wages due to increasing costs of to employers to provide employee benefits.

Household income

Household income may indirectly influence patient perception of financial burden and cost of care-related communication through health insurance and out-of-pocket expenses. Household income is the sum of all the wages received from jobs, social security, retirement annuities, unemployment benefits, public assistance, interest dividends, rental properties, child support, and informal income within a housing unit (Galobardes, Shaw, Lawlor, Smith, & Lynch, 2006). Income has more proximal, direct effects on material resources than wealth (Galobardes et al., 2006). Household income may affect health insurance status since Medicaid and state-sponsored health plans have income requirements for eligibility (Centers for Medicare and Medicaid Services, 2011). Patient health insurance status may also affect income. Benefits for employer sponsored insurance are paid in large part out of employee wages (Baicker & Chandra, 2008). Since 2000, average insurance premiums for family coverage have risen 114%, and 50% of workers with family coverage and 30% of individuals with single coverage pay more than 25% of their total premium through their wages (Kaiser Family Foundation, 2010). Household income may also directly influence perceptions of financial burden; low income parents of children with asthma report these burdens (Patel et al., 2012). Household income may also influence communication. Among patients with low income, levels of verbal activity are low in the clinical encounter and they receive less information (Waitzkin, 1985; Pendleton & Bochner, 1980; Bain, 1979).

Patient demographic factors

Patient demographic factors such as educational attainment, employment status, total number of individuals in the household, and marital status may indirectly influence perceptions of financial burden and subsequent cost of care-related communication through household income. Females disproportionately represent single parent households (Blackwell, 2010), and are also the primary caretakers of chronically ill children, which may reduce their earning potential (Hobbs et al., 1985). Other work has also shown that among women, global perceived stress is higher for those who are single or unemployed (Brown & Siegel, 1988). The total number of individuals who occupy a housing unit must also be considered when accounting for household income (U.S. Census Bureau, 2011). The number of individuals supported on a household income also determines eligibility for Medicaid insurance, and is used to determine federal poverty thresholds (Centers for Medicare and Medicaid Services, 2011; U.S. Department of Health and Human Services, 2011).

Educational attainment refers to the number of years of education received, and may also indirectly influence cost of care-related communication. There is a strong correlation between educational attainment and social status and income (Day & Newburger, 2002); higher status enables more freedom with coping with certain types of stresses whereas lower status has been linked to more disruptive life events, unemployment and fewer economic resources. Stress related to educational attainment may impact perceptions of financial burden with healthcare and patient-provider communication (Pincus & Callahan, 1995). More educated patients receive more physician time and more explanations (Waitzkin, 1985), more emotional support (Korsch, Gozz, & Francis, 1968), and clinicians display greater receptivity to psychosocial concerns (Roter & Hall, 2006) in comparison to their patients with less educational attainment. Patients who also report missed opportunities to discuss cost with their health care provider are less likely to have a college education (Alexander et al., 2004(a)).

Patient intrapersonal factors

Patient intrapersonal factors (knowledge of medical costs, beliefs and self-efficacy about cost-related communication) may directly influence cost of care-related communication in the clinical encounter, and also have a theorized, reciprocal dynamic relationship with patient contextual factors. Knowledge of costs is patients' ability to recall their copayments or out-of-pocket expenses. Data have shown that between 40-70% of patients are unaware of their copayments, or specific information about their insurance plan; these patients are less likely to discuss cost with their physicians (Benedetti et al., 2008; Shrank et al., 2006(b)). Beliefs about cost of care-related communication refer to convictions that patients have about the role of cost in treatment considerations. Some patients prefer not to have costs considered in treatment recommendations and decisions (Alexander et al., 2005) or believe it is inappropriate to discuss cost in the clinical encounter (Beneditti et al., 2008). It is likely that such patients may not want to discuss cost with their health care provider. Patient self-efficacy about cost of care-related communication refers to their self-confidence in initiating cost-related discussions with their physician. Some patients report discomfort in initiating cost-related discussions with their physicians (Alexander et al., 2004(a)), and may have low self-efficacy.

Physician contextual factors

Although this dissertation is only empirically examining the patient perspective, the physician plays an integral role in how communication transpires in the clinical encounter. Including factors from the physician perspective completes a full conceptual understanding of influence of cost of care-related communication in the clinical encounter.

Culture of Medicine

Organizational or institutional culture is denoted by a wide range of social phenomena, including an organization's behavior, beliefs, values, assumptions, symbols of status and authority, myths, ceremonies and rituals, and modes of deference and subversion (Scott, Manion, Davies, & Marshall, 2003). The culture of medicine considers the physician an expert of medical knowledge, whose strenuous training presents an unbridgeable competence gap with the lay world (Roter & Hall, 2006). The majority of medical education in the U.S. is anchored in the basic sciences, which determines the predominant view that physicians bring to medical practice (Roter & Hall, 2006). Additionally, the practice of medicine in the U.S. in recent decades has become highly litigious, impacting physician practice patterns (Baicker, Fisher & Chandra, 2007). The culture of medicine may influence cost of care-related communication because physicians have been trained to treat the biomedical basis of illness, and may be practicing defensive medicine in the form of costly services and procedures to avoid malpractice suits.

Medical training is conceptualized as the specialty in which physicians receive training (Khan et al., 2008). Physicians in many specialties receive little to no medical training in cost-conscious care, and possess no wider contextual understanding of patient illness experience (Cooke, 2010), which can impact patient health and may influence cost of care-related communication. The literature shows mixed findings: some studies indicate that primary care physicians are more likely to consider patients’ out-of-pocket costs (Shrank et al., 2006(b)), while other studies show that costs are less likely to be discussed among cardiologists or pediatricians (Patel et al., 2009; Tarn et al., 2008).

Incentives are conceptualized as the payment that physicians receive in return for providing medical services. Health plans vary widely in terms of levels of reimbursement for care, with private insurance providing more reimbursement than public insurance programs such as Medicaid (Bodenheimer, Berenson, & Rudolf, 2007). The U.S. health care system reimburses physicians based on services rendered and not on patient outcomes or quality of care, which may influence cost of care-related communication by incentivizing physicians to provide services beyond those they would offer as unbiased agents for their patients (Aaron & Ginsburg, 2009). Differences based on patients' health insurance are evident, as physicians are more likely to keep costs in mind for their Medicaid and self-paying patients (Shrank et al., 2006(b); Reichert et al., 2000), but not those who are privately insured (Patel et al., 2009).

The clinical practice setting is the environment in which physicians practice medicine. The clinical practice setting of physicians may influence cost of care-related communicated because physicians' financial relationships are often assigned to their practice group, who themselves have financial incentives through contractual arrangements with both multiple payers and individual physicians (Reschovsky, Hadley, & Landon, 2006). Practice differences are evident in cost of care-related communication with such discussions more likely to occur among physicians practicing in community and academic settings, and smaller group practices, and less likely to occur in hospital settings (Beran et al., 2007; Alexander et al., 2003).

Clinical guidelines are specific practice recommendations for the diagnosis and treatment of a disease, and give best practices for ideal clinical outcomes without explicit mention of financial costs that patients incur. Interpretation of clinical guidelines in treatment decisions may influence cost of care-related communication because the lack of mention of cost in guidelines implies that it is invisible in decision-making. Some data support this assumption. For example, increasing patient costs in osteoporosis treatment did not change physician adherence to clinical guidelines (Sinsky, Foreman-Hoffman, & Cram, 2008).

Physician intrapersonal factors

Several studies show that physicians cite lack of knowledge of costs and patient formularies as a barrier to cost of care-related communication with their patients (Beran, et al., 2007; Shrank et al., 2006(a)). Some physicians have specific beliefs about cost of care-related communication. Among a sample of medical oncologists, 20% believe cost has no role in the clinical encounter (Schrag & Hanger, 2007). Self-efficacy may also impact cost of care-related communication, as physicians cite discomfort as a common barrier to not discussing costs with their patients (Alexander et al., 2005). Demographic perceptions of patients may also influence cost of care-related communication. A large body of work suggests that patient-related factors such as socioeconomic status and race influence clinical decision making and pose major challenges to evidence-based practice (Hajjaj, Salek, Basra, & Finlay, 2010).

Social class origin comprises childhood indicators of socioeconomic position (SEP) such as parental education, occupation, and household income, all of which strongly predict SEP in adulthood (Galobardes, Lynch, & Smith, 2007). Sixty-percent of medical students come from families within 20% of the highest income bracket (as cited in Roter & Hall, 2006, p. 82). Social class origin may influence cost of care-related communication because studies show that physicians who rose to the middle class report greater attitudinal acceptance and verbal accommodation to consumerist-type challenges than physicians who originally come from upper class backgrounds (as cited in Roter & Hall, 2006, p.83).

Years in medical practice may also influence cost of care-related communication, since studies show resident physicians are less cost-conscious than attending physicians (Reichert et al., 2000). The race/ethnicity of physicians may also influence cost of care-related communication, as race discordance between patients and physicians results in more negative ratings for physician communication (as cited in Roter & Hall, 2006, p.78). Gender may likewise influence cost of care-related communication. Female physicians engage in more psychosocial and emotional discussion with patients than male physicians, and display more warmth, responsiveness and empathy (Roter & Hall, 2006).

Cost-related communication & proximal and distal outcomes

Cost of care-related communication may lead to patient satisfaction with care and a cost-sensitive treatment plan, which may encourage patients to follow the treatment plan in the short-term because the cost has been reduced. Following the treatment plan in the short-term may lead to continued patient satisfaction with care and following the treatment plan in the long-term, which in turn may lead to improved patient health outcomes of health care use.

Patient satisfaction refers to the evaluation of the care that a patient receives and is a clinical outcome that gives physicians several incentives to communicate effectively with their patients. When patients are happy with the communication and rapport the physician has established with them, there is much greater likelihood that they will comply with instructions (Shelton, 2000). Patients who receive more information or engage in more psychosocial dialogue with their physician also report higher levels of satisfaction (Roter & Hall, 2006).

A cost-sensitive treatment plan is a revised treatment plan that has occurred as a result of cost of care-related communication, and may lead the patient to follow the treatment plan as recommended in the short-term. Previous work has shown that cost of care-related discussions with a physician have resulted in patients receiving a cost-sensitive treatment plan (Beard et al., 2010).

Following the treatment plan in both the short-term and long-term due to reduced cost falls under the broader term of compliance. Compliance is conceptualized in the literature as the extent to which people follow their doctor's orders; however, it assumes that individuals must put aside their own beliefs and circumstances to follow orders that may not be working, accessible, or simply clinically inappropriate (Mellins, Evans, Zimmerman, & Clark, 1992). Some have proposed a conceptualization of compliance that considers the extent to which people follow a therapeutic plan that the patient has had active involvement in formulating (Mellins et al., 1992). The compliance factors in this model are similarly defined. The tailoring of asthma management plans among women with asthma predicts increased compliance with asthma medication use, which assume that patients are better able to follow the treatment plan in the short-term (Clark, Ko, Gong, & Johnson, 2012). Symptom reduction from following the treatment plan in the short-term may also influence patient satisfaction with care (Jackson, Chamberlin, & Kroenke, 2001).

Following the treatment plan in the short-term may enable patients to continue following the treatment plan in the long-term because the cost has been reduced, which may lead to continued satisfaction with care. In a long-term assessment of negotiated asthma treatment plans among women with asthma, patients continued to rate their physicians care favorably (Patel et al., 2012(b)). Following the treatment plan in the long-term may influence distal outcomes of patient health, specifically reduced urgent care use (emergency department visits, hospitalizations, unscheduled office visits). Tailored elements of a treatment plan that enable self-management are associated with reduced urgent care use (Gibson et al., 2003). Alternatively, among children with asthma, higher cost-sharing has shown high associations with medication underuse and higher rates of subsequent asthma-related hospitalization and emergency department visits (Karaca-Mandic et al., 2012). Perceptions of financial burden also demonstrate associations with asthma-related urgent care use (Patel et al., 2012). Such associations may similarly be apparent in adults, and communication between clinician and patient may prove to increase patients’ ability to manage their asthma and require less urgent care use for exacerbations.

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CHAPTER 3

DATA & METHODS OVERVIEW

This dissertation uses data collected as part of the baseline assessment of the Women of Color and Asthma Control study, a two-armed, randomized controlled trial (RCT) evaluating a self-management program for asthma. The RCT was funded by the National, Heart, Lung, and Blood Institute of the National Institutes of Health (1R18HL094272 01). All study procedures were approved by the Institutional Review Board of the University of Michigan Medical School. A full description of measures and methods are described in the next three chapters.

Sample

The participants were African American women with asthma. Participants were recruited from clinics within the University of Michigan Health System (UMHS), through Blue Cross Blue Shield of Michigan, and through the community. Inclusion criteria for women were 1) self-identity as African American, 2) 18 years of age or older, 3) 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, 4) access to a telephone, and 5) not pregnant (Janevic et al., 2012).

In order to assess for potential clustering of responses on outcomes by individuals seen by the same health care provider or who seek care in the same clinic, intraclass correlation coefficients (ICC) were calculated in SAS 9.3. For individuals seen by the same doctors, the ICC's for the main outcomes of interest in this dissertation were as follows: perceptions of financial burden (ICC=0.30), frequency of cost of care-related communication (ICC=0.33), preferences for cost of care-related communication (ICC=0.36), urgent office visits for asthma (ICC=0.76), emergency department visits for asthma (ICC=0.65), and hospitalizations for asthma (ICC=0.23). For individuals seen in the same clinics, the ICC's for the main outcomes of interest in this dissertation were as follows: perceptions of financial burden (ICC=0.35), frequency of cost of care-related communication (ICC=0.37), preferences for cost of care-related communication (ICC=0.36), urgent office visits for asthma (ICC=0.72), emergency department visits for asthma (ICC=0.59), and hospitalizations for asthma (ICC=0.30). Design effects were calculated with average cluster size for both doctors and clinics. Design effects were not greater than 2, which typically do not result in overly exaggerated rejection proportions at the 5% level (Muthen & Satorra, 1995). Therefore, clustering was ignored for these variables in the analysis of this dissertation. This suggests a conservative analysis where standard errors may be larger and confidence intervals may be wider than would be obtained when accounting for clustering. All factors found to be significant in these analyses would remain significant if clustering was accounted for. However, one consequence is that not accounting for clustering may fail to identify some significant factors which otherwise would be found when clustering is accounted for.

Data

This dissertation utilized data from item-specific surveys, in-depth interviews, and focus groups. Qualitative data served a dual purpose which included providing supporting information for the quantitative findings, and providing themes for select questions for which quantitative data were not available, such as aspects of asthma management perceived as burdensome and options offered to women by health care providers. Several approaches to combining qualitative and quantitative data exist for mixed methods (Creswell, 2008). The next three chapters present the results using a concurrent embedded strategy mixed methods analysis. Concurrent embedded strategy in this dissertation considers quantitative methods as the primary technique that guides the analysis, into which qualitative data is nested to describe the experience of participants and expand an understanding of what the quantitative results may mean (Creswell, 2008). The analysis often brings qualitative data into a results section in support of the quantitative findings to provide more perspective on participant experiences or constructs under investigation (Creswell, 2008).

Item-specific survey data

Item-specific survey data from baseline data collection were available for 343 participants. Data were collected through hour-long, telephone interviews by trained interviewers and select variables were verified through medical records. All participants provided written informed consent to provide data for this study and have their medical records reviewed. Participants received modest monetary compensation for their participation.

Focus Groups

Participants identified in the baseline survey interview who reported preferences for cost of care-related communication were re-contacted via recruitment letters and follow-up phone calls for participation in one of two 90-minute focus groups (total n=14) to examine financial-related perceptions and experiences in the clinical encounter with addressing these concerns. Focus groups allow for the collection of in-depth data that reflect the heterogeneity of the study sample. Another advantage is that focus groups allow respondents to react to and build upon the responses of other group members through a synergistic effect that may not be uncovered in individual interviews (Stewart & Shamdasani, 1990).

Focus groups were carefully composed based on maximum variation sampling procedures (Patton, 1987), whereby each focus group was homogenous based on their health insurance status (full or partial coverage), and heterogeneous based on variation in self-report responses to the presence of multimorbidity, perception of financial burden with asthma care, frequency of cost of care-related communication with their health care provider, and years since their initial asthma diagnosis. The full insurance group included individuals with Medicare and supplemental coverage, Medicaid, and other government insurance. The partial/no insurance group included individuals with private insurance, Medicare-only, or no insurance. Sub-study procedures received prior approval from the University of Michigan Medical Institutional Review Board (IRB) before initial contact with participants.

The discussion guide for the focus groups was developed with relevant open-ended questions and probes based on a review of the literature and feedback from experts who have extensive experience working with the target population. Focus groups were facilitated by two, trained individuals (Minal Patel and Effat Iddeen). Participants provided written, informed consent prior to data collection and received monetary compensation for their time and participation. Discussions were recorded and transcribed by a professional service and data cross-examined for accuracy.

In-depth interviews

Twenty-five participants who identified themselves as having type 2 diabetes, heart disease, or arthritis in the baseline survey interview were approached for their participation in a qualitative sub-study of in-depth interviews examining disease self-management experiences.

These comorbidities were selected because they are highly prevalent conditions that are likely to impact asthma self-care. Sub-study procedures received prior approval from the University of Michigan Medical Institutional Review Board (IRB) before initial contact with participants. Questions in the interview protocol were developed using domains identified in the existing literature and underwent expert review with individuals who have extensive experience working with the target population. Participants provided additional written, informed consent to participate in this sub-study, and received modest monetary compensation for their participation. Interviews were conducted by trained interviewers, recorded, and transcribed. In-depth interviews permit greater flexibility and individualization; however, they are limited by the extent to which individuals differences and circumstances can be queried (Patton, 2002). Additionally, in this study, the interview guide was created for another research question and coded for themes relevant to this dissertation; the ability to ask focused questions relevant to hypotheses in this dissertation was limited. Focus group data provided illustrative examples where in-depth interview data were limited.

The next three chapters describe the rationale, methods, and results of three individual papers that examine the aims of this study utilizing the aforementioned data: Chapter four, Who perceives health-related financial burden and why among women managing asthma; Chapter five, Who prefers to discuss the cost of their care with their health care provider and why among women with asthma; and Chapter six, Cost of care-related communication in the clinical encounter and asthma outcomes among women with asthma. Chapter seven concludes with a summary of the main findings from the next three chapters, their significance, and next steps for research, clinical practice, and intervention.

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CHAPTER 4

WHO PERCEIVES HEALTH-RELATED FINANCIAL BURDEN AND WHY AMONG WOMEN MANAGING ASTHMA

Abstract

Asthma is a prevalent chronic condition where associated costs to patients can be high. In the current economic climate, rising health care costs are being shifted more frequently to patients. The purpose of this study was to 1) identify economic factors that mediate patients' clinical and demographic characteristics and perception of asthma-related financial burden and, 2) examine aspects of asthma management perceived as financially burdensome. Data were collected through standardized telephone interviews from a study cohort of 343 African American women seeking services for asthma in Southeast Michigan. Additional qualitative data were collected through sub-samples via two focus groups (n=14) and in-depth interviews (n=25) to provide supporting information. Coded transcripts were analyzed for themes. The relationships between perceptions of financial burden and clinical and demographic factors were examined through hypothesized mediators (household income, health insurance, out-of-pocket expenses). Quantitative data were analyzed using path analysis. The mean age of participants was 42.8 years (SD=14.82). Fifty two percent (n=180) of participants perceived financial burden. Household income, health insurance, and out-of-pocket expenses explained the pathway between perceptions of burden and 1) being married (β= 0.068, SE=0.026, $p<0.01$), 2) having some college (β= 0.056, SE=0.024, $p<0.05$) and a college education or more (β= 0.099,

SE=0.034, $p<0.05$), and 3) part time ($\beta= 0.043$, SE=0.021, $p<0.05$) and full time employment ($\beta= 0.086$, SE=0.031, $p<0.01$). For individuals with partial/no insurance ($\beta= 0.314$, SE=0.100 $p<0.01$) and full insurance ($\beta= 0.632$, SE=0.134, $p<0.001$), more out-of-pocket expenses were associated with more perceptions of burden. Burden may be present despite having economic resources and health insurance, and such individuals may also be at risk for poor outcomes. Awareness of factors beyond access alone that may contribute to perceptions of financial burden may be needed by clinicians to assist patients who need help understanding options to reduce such burden.

Introduction

Asthma is a prevalent chronic condition marked by adverse health outcomes and high associated costs (Akinbami, Moorman, & Liu, 2011). Chronic diseases like asthma require lifetime management with a therapeutic regimen and routine interface with the health care system in order to adjust medications and the treatment plan, monitor exacerbations, and guide self-management effort. This requirement can be perceived as financially burdensome in an economic climate in which rising health care costs are being shifted more frequently to patients, and health insurance plans do not provide full coverage for the broad spectrum of services required to manage a chronic condition. Health-related financial burden may be actual, as in inadequate insurance coverage, or perceived based on insufficient information regarding alternative options.

Six studies describe financial barriers associated with asthma care, and 20% of adults with asthma report these barriers (Patel, Brown, & Clark, 2012; Karaca-Mandic, Jena, Joyce, & Goldman, 2012; Knoeller, Mazurek, & Moorman, 2011; Nguyen, Zahran, Iqbal, Peng, & Boulay, 2011; Newcomb, McGrath, Covington, Lazarus, & Janson, 2010; Scal, Davern, Ireland,

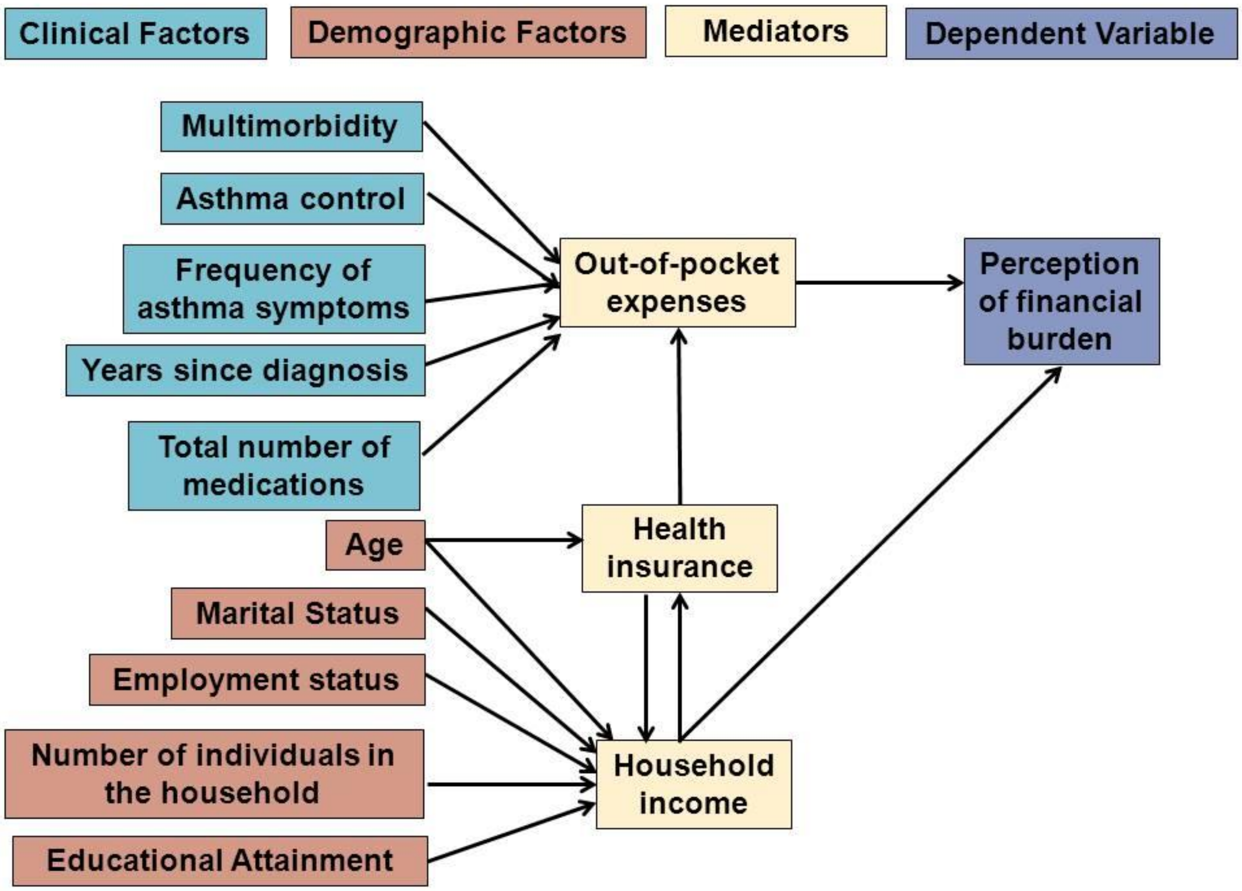
& Park, 2008). National data show that adults with asthma who report financial barriers with asthma care are more likely to be nonelderly adults, female, African American or Hispanic, low income, uninsured, not employed, and have poorly controlled asthma (Knoeller et al., 2011). Measures in existing studies operationalize health-related financial barriers as a behavioral response, such as delaying care, and lack a precise measure of *perceptions* of financial burden, i.e. one’s subjective experience based on their own appraisal. Only one study has explored perception of financial burden with asthma care in a pediatric population; it found female heads of household and lowest of low income individuals as significant direct, predictors of perceptions (Patel et al., 2012), but did not clarify the pathways through which financial burden occurs. To date, no studies have explored the pathways through which patients’ demographic and clinical characteristics influence perceptions of financial burden with asthma care, particularly in vulnerable populations.

African American women comprise a vulnerable population where perceptions of health-related financial burden merit further exploration. 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 (Centers for Disease Control and Prevention, 2011). They have increased asthma-related risk exposures and may be vulnerable to perceiving financial burden with asthma management due to racial and gender disparities in economic opportunities that persist within this population (Jackson & Williams, 2006).

In an era of financial stress, it is important to expand capacity to provide simple, low cost improvements in patient care that will enable individuals with chronic conditions to take full advantage of available treatments and interventions. Further investigation of factors associated with perceptions of financial burden may help clinicians better anticipate which patients are most concerned with financial burden and need help to clarify their perceptions and/or help to better understand their options. Some evidence suggests that clinicians change their practice patterns based on their perceptions of patients' ability to pay given the type of health insurance they have (Patel, Coffman, Tseng, Clark, & Cabana, 2009; Reichert, Simon, & Halm, 2000). For example, being less mindful of costs for privately insured patients even though out-of-pocket expenses are often much higher for privately insured patients compared to individuals on government sponsored plans (Patel et al., 2009). Further investigation of how burden manifests from health insurance merits further exploration.

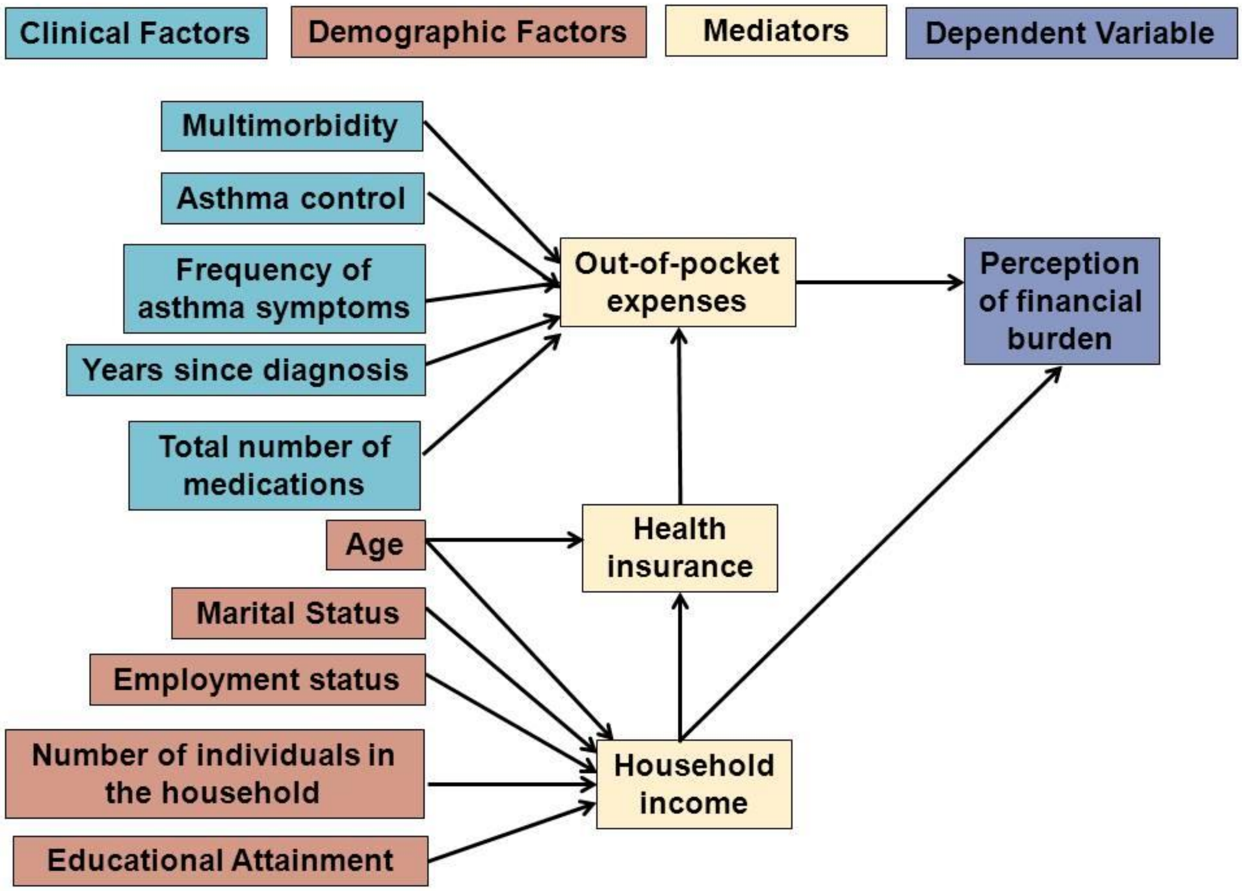
The purpose of this study was to examine the direct and indirect relationships between economic, demographic, and clinical characteristics of African American women with asthma and perceptions of financial burden, and describe aspects of asthma management perceived as financially burdensome. Economic factors (health insurance, out-of-pocket expenses, household income) may mediate relationships between patients' perception of financial burden and their demographic factors (educational attainment, number of individuals in the household, age, marital and employment status) and clinical factors (multimorbidity, asthma control, frequency of asthma symptoms, years since initial asthma diagnosis, total number of medications) (see Figure 4.1).

Figure 4.1: Conceptual model depicting influences of perception of financial burden.



In Figure 4.1, household income and health insurance demonstrate a reciprocal relationship, as theoretical support suggests that health insurance and income affect each other (Baicker & Chandra, 2008). Preliminary analysis showed that the effect of health insurance on income did not demonstrate a significant relationship in this sample, therefore this relationship was dropped in order to simplify the model and only the effect of income on health insurance was estimated. Figure 4.2 shows the analytical model that was empirically tested in this study.

Figure 4.2: Analytic path model depicting influences of perception of financial burden.



This study explored three hypotheses depicted in Figure 4.2:

Hypothesis 1: The relationship between demographic factors and perception of financial burden will be mediated through household income, health insurance, and out-of-pocket expenses.

Hypothesis 2: The relationship between clinical factors and perception of financial burden will be mediated through out-of-pocket expenses.

Hypothesis 3: Health insurance will have a moderating effect on the relationships in hypotheses 1 and 2.

Methods utilized in this study are described next, followed by results, and a discussion of the findings.

Methods

Data Source

Item-specific survey data came from the baseline assessment of a two-armed, randomized controlled trial (RCT) evaluating a self-management program for women with asthma. All study procedures were approved by the Institutional Review Board of the University of Michigan Medical School.

Sample

Participants were African American women with asthma 18 years of age or older with physician-diagnosed asthma, based on National Asthma Education and Prevention Program (NAEPP) Expert Guidelines on the Diagnosis and Management of Asthma (National Asthma Education and Prevention Program [NAEPP], 2007). 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 women were: 1) self-identity as African American, 2) 18 years of age or older, 3) 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, 4) access to a telephone, and 5) not pregnant (Janevic et al., 2012). Of the 408 participants initially recruited, 343 provided baseline data. The response rate was 84%. Participants provided written informed consent to provide data for this study and have their medical records reviewed. Participants received modest monetary compensation for their participation. The quantitative findings presented here reflect data from 343 participants who provided baseline data.

Data Collection and Measures

All data were collected through hour-long telephone calls conducted by trained interviewers. Items in the data collection survey instrument were constructed and adapted based on review of the literature. Participants were asked to provide demographic and asthma-specific information, particularly as it relates to their experiences with self-management.

Variables were operationalized as follows:

Perceptions of health-related financial burden

The main outcome of interest in this study was perceptions of financial burden. Perceptions of health-related financial burden measured subjective experience of financial difficulties and hardship experienced by the participant due to resources required for asthma management. The single-item measure included: “Do you consider cost to be a problem in managing your asthma?” The interviewer prompt defined ‘problem’ as either not paying the bills because they could not be afforded or paying them despite financial hardship. A similar subjective measure to assess patient financial burden with a general population of adults was used in previous work (Tseng et al., 2007). Self-report measures are appropriate and preferred measures for perception of health-related financial burden because they capture a subjective experience. The final measure of perception of financial burden was used as an ordinal variable in this study.

Participants who reported perceptions of health-related financial burden were also asked, “What aspects of your asthma management are costly to you?” Sub-elements for this question included asthma medication (quick relief, long-term controller), asthma devices (peak flow meter, spacer, nebulizer), health care visits (physician office visits, urgent care visits, hospitalizations), lost work time, and other, all assessed on a 5-point Likert scale ranging from none of the time to all of the time.

Economic factors (Mediators)

Total out-of-pocket expenses

Out-of-pocket expenses were conceptualized as health care expenses that a participant incurred that were not covered by health insurance for their asthma care. Specific measures for indirect expenses (such as lost-work time or transportation expenses) were not available in the data source; therefore, out-of-pocket expenses in this study was limited to direct costs of medications and operationalized as such. To measure out-of-pocket costs, participants were asked a series of questions through an open-ended format. They were first asked to name each medication they take for their asthma through an open-ended response. Participants were then asked, “In the past 12 months, how many times did you refill this medication?” with response choices between 1-12 and other. Finally, participants were asked “how much did you pay out-of-pocket each time you refilled this medication?” with an open-ended response choice. In order to obtain total-out-of-pocket expenses, each out-of-pocket payment was multiplied by the number of refills and summed to obtain total expenses over the past year for all asthma medications, and rounded to the nearest dollar. The final measure of total-of-pocket expenses for this study was a count variable.

Health insurance

To measure what type of health insurance participants had, they were first asked if they were covered by any kind of health insurance or health plan (y/n). If participants answered ‘yes’ they were then asked what kinds of health insurance or health coverage they had and to select all that apply. Response choices were ‘private health insurance’, ‘Medicare’, ‘Medi-Gap’, ‘Medicaid’, ‘military health care’, ‘Indian Health Service’, ‘state-sponsored plan’, ‘other government program’, ‘single service plan.’ Based on average out-of-pocket costs associated with types of health insurance available in the U.S. health insurance market (Kaiser Family Foundation, 2012), 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.” With self-report, data have shown that assessments that ask whether one has health insurance, the kind of health insurance, and multiple sources of coverage ascertained in that order withstand cognitive interviews well (Call, 2003). Verification of health insurance status through medical record review was computed with Cohen’s Kappa. The proportion of agreement was found to be high and statistically significant ($\rho_0 = 0.69$, $p<0.001$).

Household income

Household income was measured by asking participants the following question: “What is your annual household income? Please stop me when I get to the category that best describes your household income.” Response choices included increments of ten thousand for a total of 11 categories, ranging from $5,000 or less to $80,001 or more. This measurement of household income is consistent with recommendations from the social epidemiological literature of using pre-defined categories for respondents to classify themselves (Galobardes, Shaw, Lawlor, Smith, & Lynch, 2006). However, self-report of income continues to be a sensitive question among respondents (Groves et al., 2004), and this measure may still have some reliability concerns due to social desirability. The final measure of income was used as an ordinal variable in this study.

Clinical factors

Multimorbidity

Multimorbidity was operationalized as the number of chronic medical conditions that a participant was managing in addition to asthma. Multimorbidity was measured by asking participants the following question: “Has a doctor ever told you that you have any of the following medical conditions: hypertension, diabetes, chronic heart disease, arthritis or joint problems, cancer, gastroesophageal reflux disease, atopic dermatitis, recurrent pneumonia, chronic bronchitis, depression, anxiety, bipolar disorder, schizophrenia, or other (with several response options), with a binary response option (yes/no). This measure is consistent with other work that has used a pre-specified list of conditions to guide respondents self-report (Tseng, Brook, Keeler, Steers, & Mangione, 2004). Self-report of health conditions provide reasonable comparison with health records, demonstrating an overall weighted kappa of 0.51 (Barber, Muller, Whitehurst, & Hay, 2010). The final measure for multimorbidity in this study was a count variable.

Frequency of symptoms

Frequency of asthma symptoms was operationalized as how often participants’ experienced symptoms of asthma. Responses were measured based on definitions in the NAEEP asthma guidelines (NAEPP, 2007). To assess asthma symptoms, participants were asked the following question: “In the past 4 weeks, on average, how many days a week did you have daytime asthma symptoms?” Response choices included two or less days per week, three or more days per week, and throughout the day. Nighttime symptoms were highly associated with participants’ daytime symptoms in this sample ($X^2(4) = 68.71$, $p<0.001$).The final measure of frequency of symptoms was used as categorical variable in this study.

Asthma control

Asthma control was operationalized as current impairment and future risk concerning a participants' asthma after therapy was initiated (NAEPP, 2007). Asthma control was measured using the Asthma Control Test (ACT), a five-item instrument that assesses symptoms, rescue medication use, and activity limitations. Evaluation of the ACT has demonstrated that it is a reliable and valid measure, and responsive to changes in asthma control over time (Schatz et al., 2007). Internal consistency reliability of the ACT is 0.79, test-retest reliability is 0.77, and criterion validity demonstrates significant correlations between baseline ACT scores and baseline specialists' ratings of asthma control ($r = 0.52$) (Schatz et al., 2007). The reliability of the 5-items that comprise the ACT instrument was assessed on the study sample and the Cronbach alpha of 0.799 was similar to reliability values in the literature for this instrument. The ACT is scored based on a sum of the Likert scale responses from the five items. Based on the NAEPP asthma guidelines, a score of 20 or greater indicated well controlled asthma, a score of 16-19 indicated not well controlled asthma, and a score of 15 or less indicated very poorly controlled asthma (NAEPP, 2007). The final measure of asthma control was used as a categorical variable in this study.

Years since asthma diagnosis

The length of time since asthma diagnosis was operationalized as the number of years that a participant had been living with asthma since receiving a physician diagnosis. To measure this, participants were asked the following question: "In what year were you diagnosed with asthma?" Number of years was determined by subtracting year of diagnosis from the date of the baseline interview. Responses were rounded to the nearest year. The final measure of years since asthma diagnosis was used as a count variable in this study.

Total number of medications

Total number of medications was operationalized as all medications that a participant was currently prescribed to manage all of their health conditions. The total number of medications that a participant was currently prescribed was measured by first asking participants to identify through an open-ended format which asthma medications they were currently taking. Participants were also asked if they were on medication for each chronic condition they indicated for other chronic conditions they were also managing with asthma (multimorbidity), with a response choice of yes/no. Responses to both questions were summed in order to get total number of medications. The final measure of total number of medications was used as a count variable in this study.

Specialty of the care-providing clinician

For descriptive and bivariate analysis, participants were asked if they received care from a specialty clinic (allergy or pulmonology) or from a primary care physician with the following questions "would you please tell me the name of the primary care physician you see most often for your asthma" and "would you please tell me the name of the asthma specialist you see most often for your asthma." Responses were coded into "primary care only", "primary care and specialty", "specialty only", and "no doctor." The final measure of specialty of the care-providing clinician was used as categorical variable in this study.

Demographic factors

Marital status

To measure marital status, participants were asked the following question: "What is your current marital status?" with response choices of single or never married, married, unmarried partner, divorced, widowed, separated. The final measure of marital status was used as categorical variable in this study.

Employment status

Employment status was operationalized as how often an individual reported working. This was measured through a series of two questions. Participants were first asked if they were employed outside the home or self-employed (yes/no), and then a sub-question among those who were employed asking whether they work full time (yes/no). The final measure of employment status was used as categorical variable in this study.

Educational attainment

Educational attainment was operationalized as the highest level of formal education achieved. To measure this, participants were asked the following question: "What is your highest education level?" with the following response choices: never attended school, less than high school, high school graduate or GED, vocational technical, some college or associate degree, college degree, advanced graduate degree, other. The final measure of educational attainment was used as categorical variable in this study.

Age

Age was measured by asking participates their date of birth. Current age was calculated by subtracting date of birth from the date that participants' baseline interviews were completed. Responses were rounded to the nearest year. The final measure of age was used as a count variable in this study.

Total number of individuals in the household

Number of individuals in the household was operationalized as the number of persons that reside within the household of the participant. This was assessed through a series of questions. Participants were asked if there were currently any children living in the household with a binary response choice (yes/no). Two follow up questions asked participants how many children between the following ages were currently living in their home: 0-1 years, 2-3 years, 4-6 years, 7-12 years, 13-18 years, older than 18; and how many children living in their household they were responsible for, assessed with an open-ended response. Lastly, participants were asked if they were a caregiver for an older relative, which was assessed with a binary response choice (yes/no). The number of individuals in the household was assessed by taking a sum of these measures, including the respondent and a spouse or partner based on their response to marital status. The final measure of number of individuals in the household was used as a count variable in this study.

Qualitative methods

In-depth interviews

Twenty-five participants who identified themselves as having type 2 diabetes, heart disease, or arthritis in addition to asthma in the baseline survey interview were approached for their participation in a qualitative sub-study of in-depth interviews examining disease self-management experiences. These comorbidities were selected because they are highly prevalent conditions that are likely to impact asthma self-care. Sub-study procedures received prior approval from the University of Michigan Medical Institutional Review Board (IRB) before initial contact with participants. A sample size of 25 was chosen based on similar qualitative studies of chronic illness experience, and determined by investigators to be the point at which data saturation was expected. Of the 41 participants who were initially approached, 5 were ineligible, 9 could not be reached, 1 refused, and 1 did not show up for the interview. Twenty-five participates were interviewed. Questions in the interview protocol were developed by another investigator for the purposes of another research question, using domains identified in the existing literature (See Appendix 4A for the full discussion guide). The discussion guide underwent expert review with individuals with extensive experience working with the target population. Participants provided additional written, informed consent to participate in this sub-study, and received modest monetary compensation for their participation. Interviews were conducted by another investigator and trained interviewers, recorded, and eventually transcribed.

Focus Groups

Participants identified in the baseline survey interview who reported preferences for cost of care-related communication were re-contacted via recruitment letters and follow up phone calls for participation in one of two 90-minute focus groups to examine financial-related perceptions with asthma management and experiences in the clinical encounter with addressing these concerns. Focus groups were carefully composed based on maximum variation sampling procedures (Patton, 1987), 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 multimorbidity, perception of financial burden, frequency of cost of care-related communication, and years since their initial asthma diagnosis. The full insurance group was defined as individuals with Medicare and supplemental coverage, Medicaid, and other government insurance. The partial/no insurance group was defined as individuals with private, Medicare-only, or no health insurance. Of the fifty participants who met inclusion criteria for the focus groups, 30 were randomly selected to be contacted. Nine agreed to participate in the partial/no insurance group; of these, 8 participants provided consent. In the full insurance group, 10 individuals agreed to participate, and 6 provided consent. Of the remaining participants who were contacted, 3 refused, and 8 could not be contacted. Study procedures received prior approval from the University of Michigan Medical Institutional Review Board (IRB) before initial contact with participants.

The moderator's guide was designed to elicit conversation around financial-related perceptions with asthma management and experiences with health insurance coverage for asthma-related services (See Appendix 4B for the full discussion guide). Twelve questions and prompts were developed. The questions were based on a review of the literature and a content review of the questions was conducted with experts who have extensive experience working with the target population.

Each focus group was facilitated by the primary author and a research assistant (Minal Patel and Effat Iddeen). A note taker took field notes and was responsible for monitoring the tape recorder. Another research assistant was responsible for ensuring that all participants completed informed consent, a survey of demographic information, setting up refreshments, and providing child care. Consistency was assured across the groups through the use of a 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 (Stewart & Shamdasani, 1990).

Data analysis

Intraclass correlation coefficients (ICC) were calculated in SAS 9.3 in order to assess for potential clustering of responses on perceptions of financial burden by individuals seen by the same health care provider (ICC=0.30) or who seek care in the same clinic (ICC=0.35). Design effects were calculated with average cluster size for both doctors and clinics. Design effects were not greater than 2, which typically do not result in overly exaggerated rejection proportions at the 5% level (Muthen & Satorra, 1995). Therefore, clustering was ignored for these variables in this analysis. This suggests a conservative analysis where standard errors may be larger and confidence intervals may be wider than would be obtained when accounting for clustering. All factors found to be significant in these analyses would remain significant if clustering was accounted for.

Missing data

Missing data were ignored, since less than 5% of missing values were present on any single variable in these data (Kline, 2011).

Quantitative analysis

SAS 9.3 was used for all descriptive analyses. In order to normalize the distribution of skewed variables, out-of-pocket expenses, marital status, health insurance, number of individuals in the household, and perceptions of financial burden were collapsed into categories based on distribution and/or substantive meaning.

For economic, demographic, and clinical variables, and components of asthma management perceived as burdensome, frequencies were computed for each of the categorical variables (specialty of the care-providing clinician, asthma control, frequency of asthma symptoms, types of asthma medicines prescribed, asthma devices, health care visits, lost work time, marital status, employment status, number of individuals in the household, educational attainment, household income, health insurance), and means and standard deviations were computed for continuous variables (e.g., multimorbidity, total number of medications, years since asthma diagnosis, age, out-of-pocket expenses).

Student’s t-test for continuous variables and contingency tables with chi-square and Fisher’s exact tests as appropriate for categorical variables were used to examine differences in economic, demographic, and clinical characteristics between participants who perceived financial burden and those who did not report these perceptions. The main outcome of interest, perceptions of financial burden, was analyzed as a binary variable for bivariate analysis.

Dimensions of the contingency tables were as follows: 2x2 contingency tables were computed for marital status and head of household; 3x2 tables for household income, employment status, frequency of symptoms, asthma control, and asthma medications; and 4x2 tables for educational attainment, health insurance, and specialty of care.

Structural equation models with observed variables, specifically path analysis models, were used to examine direct and indirect relationships between clinical, economic, and demographic factors and perceptions of financial burden (See Figure 4.2). Path analysis was used because this technique allows for the specification of a model that attempts to explain why observed, measured, variables are correlated through other variables, and tests for these mediation effects through a series of regression models (Barron & Kenny, 1986; Kline, 2005). The exogenous variables in the model were clinical factors (asthma control, frequency of asthma symptoms, multimorbidity, years since asthma diagnosis, total number of medications), and demographic factors (marital status, employment status, number of individuals in the household, educational attainment, age). The endogenous variables in the model were economic factors: household income, out-of-pocket expenses, health insurance, and the outcome: perceptions of financial burden. The main outcome of interest, perceptions of financial burden, was analyzed as an ordinal categorical variable for path analysis.

Multigroup models show whether the interactions of hypothesized relationships in a model differ when stratified by another variable (Kline, 2011). To test whether health insurance (full or partial/no) had a moderating effect on the relationships in the model, a multigroup model was examined where 1) all paths were constrained to have equal values for those with full insurance and those with partial/no insurance (fully constrained); 2) only three paths were constrained (household income → out-of-pocket expenses; household income → perceptions of financial burden; out-of-pocket expenses → perceptions of financial burden) (partially constrained); and 3) all paths were free to vary between groups (unconstrained, free model). Chi-square difference tests between pairs of models were used to see whether health insurance moderated particular paths in the model.

To assess whether the sample size (n=343) provided sufficient power to detect a close fitting model, power was calculated based on power estimates from the literature for selected levels of degrees of freedom (MacCallum, Browne, & Sugawara, 1996). With a sample size of 343 and 44 degrees of freedom, power to estimate the model was 0.872. Based on another recommended assessment of sample size, the N:q rule (sample size to parameter ratio) for maximum likelihood, a ratio of 20:1 made n=343 a sufficient sample size to estimate the proposed model (Kline, 2011).

All equations were estimated simultaneously with Mplus 6.12 software. Since there were few missing data, listwise deletion was employed where cases with missing scores on any variable are excluded from the analyses. The effective sample size (only cases with complete records) was used to estimate the path models (n=316). Power to estimate the model with the effective sample size was still 0.872 as reported above. The statistical estimator used to compute the models was weighted least square parameter estimates using a diagonal weight matrix with standard errors and mean and variance adjusted chi-square test statistic that used a full weight matrix (WLSMV). This estimation method is recommended for binary or ordered dependent categorical variables (Muthun & Muthun, 2011; Kline, 2011). Mediation was tested through bootstrap methods. Bootstrapping is based on resampling with replacement which is done many times to compute the indirect effect in each sample and a sampling distribution. Bootstrapping in Mplus produced a standard error and a p-value with the indirect effect for both the standardized and unstandardized estimates. The number of bootstrap iterations requested was 500, which is a sufficient sample to provide reasonably stable estimates (Cheung & Lau, 2008). Correlation of parameter estimates were checked and none were found to be above 0.70 (Muthen & Muthen, 2011). Several criteria for assessing model fit were used, including the model chi-square statistic (seeking X^2 that was small and not significant), weighted root mean square residual (WRMR) (seeking WRMR closer to zero), Comparative Fit Index (CFI) (seeking CFI ≥ 0.90), and root mean square error of approximation (seeking RMSEA ≤ 0.08) (Kline, 2011; Hu & Bentler, 1999). These model fit criteria were used as a means of evaluating how close the model fit the data. Alpha values of 0.05 or less were considered significant for these analyses. Mediation was determined if indirect estimates had alpha values of 0.05 or less.

Qualitative analysis

To check for transcription accuracy, a review of the focus group and in-depth interview transcripts and audio-recordings was conducted. Preliminary codes were generated based on topics from the existing literature and survey instrument for the item-specific survey data, as well as review of each transcript to identify statements reflecting recurring distinct categories, concepts, or themes regarding aspects of financial burden with asthma management. Codes were refined as needed and transcripts were recoded to reflect the refined codes. Based on recommended strategies, reliability was assessed by checking transcripts to make sure they did not contain obvious mistakes and spot-checking data with codes during the coding process to ensure that there was no drift in the code definitions (Creswell, 2008). NVivo 9 software was used to organize codes.

Transcripts were coded by two independent coders (Minal Patel and Effat Iddeen). In order to enhance reliability of the analysis, all coding was reviewed and the two raters 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 (Lombard, Snyder-Duch, & Bracken, 2004). 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 (Bakeman, 2000). 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 ($\rho_0 = 0.77$).

Coded questions from in-depth interviews and focus groups were used to generate themes and illustrative examples to support the quantitative analysis and describe perceptions of financial burden associated with asthma management. Comparisons and differences in themes were made between the experiences of individuals with full health insurance coverage versus partial/no coverage as appropriate.

The results that follow first describe characteristics of the survey data sample (n=343), followed by a description of the sample that provided the qualitative data: focus groups (n=14) and in-depth interviews (n=25). Following sample characteristics are qualitative results of one aim of this study: description of specific aspects of asthma management perceived burdensome, followed by additional information regarding coping strategies. Next, bivariate results are presented between economic, demographic, and clinical characteristics and perceptions of financial burden, with qualitative supporting information. Finally, the path analytic results are presented first describing direct relationships in the model, and then the results of the three study hypotheses. Qualitative supporting information is provided as appropriate to elaborate and provide context for the quantitative findings.

Results

Survey sample characteristics

Table 4.1 describes economic and demographic characteristics of the total sample. The mean age of participants was 42.8 years (SD=14.82). Twenty-nine percent (n=100) reported being married and 67% (n=230) reported being heads of their household. Thirty-five percent (n=119) reported three or more individuals in their household. Forty-two percent (n=137) of the sample had an annual household income of less than \$20,000, 24% (n=79) between \$20,001 and \$40,000, 18% (n=57) between \$40,001 and \$60,000, and 16% (n=52) had an annual household income above \$60,001. Seventy-nine percent (n=273) reported educational attainment above the high school level. Forty-five percent (n=153) reported having private health insurance coverage, while 18% (n=62) had Medicare and supplemental insurance, 2% (n=8) had Medicare only, 27% (n=92) had Medicaid, 6% (n=22) had other government-sponsored insurance, and 2% (n=6) reported no insurance coverage. The mean total out-of-pocket expenses for asthma medications in a year was \$163.27 (SD=308.27) and the range was \$0-2,840.

Table 4.2 describes clinical characteristics of the sample. Thirty-three percent (n=113) reported seeing both a specialist and primary care provider for their asthma, while 59% (n=200) only see a primary care provider, 6% (n=21) only see a specialist, and 2% (n=8) of participants reported not having a health care provider they see for their asthma. The mean number of years since participants were diagnosed with asthma was 18.01 years (SD=14.77). Based on NAEPP classification for frequency of asthma symptoms, 61% (n=210) were found to have symptoms ≤2 days/week, while 28% (n=95) had symptoms ≥ 3 days/week, 11% (n=38) reported symptoms throughout the day.

Table 4.1: Economic and demographic characteristics of participants who do and do not perceive financial burden.

Variable	**Total sample N=343**	**Perceive financial burden (n=180)**	**Do not perceive financial burden (n=163)**	**t or X^2**
Age (mean, SD)	43.11 (14.82)	43.69 (14.21)	42.47 (15.47)	t=-0.76, *NS*
Marital status (% Married)	29% (100)	31% (56)	27% (44)	$X^2(1)=0.64$, *NS*
Head of household (% yes)	67% (230)	69% (122)	66% (108)	$X^2(1)=2.02$, *NS*
Number of individuals in the household				$X^2(3)=5.77$, *NS*
1	38% (132)	35% (62)	43% (70)	
2	27% (92)	27% (49)	26% (43)	
3	15% (51)	19% (34)	11% (17)	
4 and more	20% (68)	19% (35)	20% (33)	
Educational attainment				$X^2(2)=5.57$, *NS*
High school /GED or less	21% (70)	16% (28)	26% (42)	
Some college, associate's degree, or vocational school	47% (162)	49% (89)	45% (73)	
College or above	32% (111)	35% (63)	29% (48)	
Employment status				$X^2(2)=2.56$, *NS*
Part-time	26% (87)	30% (52)	22% (35)	
Full-time	39% (131)	37% (65)	42% (66)	
No employment	35% (114)	33% (57)	36% (57)	
Household income				$X^2(3)=7.21$, *NS*
<$20,000	42% (137)	39% (67)	46% (70)	
$20,001 - $40,000	24% (79)	29% (50)	19% (29)	
$40,001 - $60,000	18% (57)	19% (33)	15% (24)	
>$60,001	16% (52)	13% (22)	20% (30)	

Table 4.1: Continued

Variable	Total sample N=343	Perceive financial burden (n=180)	Do not perceive financial burden (n=163)	t or X^2
Health insurance				**$^{a}X^{2}(3)=14.24$****
No insurance	2% (6)	3% (5)	1% (1)	
Private	45% (153)	50% (89)	39% (64)	
Medicare only	2% (8)	2% (4)	2% (4)	
Medicare + supplemental coverage	18% (62)	15% (28)	21% (34)	
Medicaid only	27% (92)	21% (37)	34% (55)	
Other government	6% (22)	9% (17)	3% (5)	
				$X^{2}(1)=5.02$*
[b]Full health insurance	51% (176)	46% (82)	42% (69)	
[c]Partial/no health insurance	49% (167)	54% (98)	58% (94)	
				t=-4.74***
Out-of-pocket expenses (mean, SD)	\$163.27 (308.27)	\$234.08 (378.33)	\$85.04 (175.60)	
(Range)	\$0-\$2,840	\$0-\$2,840	\$0-\$998	

Student's t-test and chi-square tests were performed on demographic variables of interest to identify differences between the groups. NS= not significant. Level of significance reported as (p-value): *p<.05, **p<.01, ***p<.001.

a. Due to low cell count, chi-square test is based on the associations between private, Medicare + supplemental coverage, Medicaid only, and other government.
b. Partial insurance= private, no insurance, Medicare only.
c. Full insurance= Medicaid, Medicare and supplemental coverage, other government insurance.

Based on NAEPP classification for asthma control, 30% (n=101) had well-controlled asthma, 31% (n=107) had not well controlled asthma, and 39% (n=135) had poorly controlled asthma. The mean number of other medical conditions with asthma was 3.65 (SD=2.57), and the mean number of medications prescribed for all medical conditions including asthma was 5.32 (SD=2.88). Fifty-two percent (n=180) of women in this sample perceived financial burden.

Table 4.2: Clinical characteristics of participants who do and do not perceive financial burden.

Variable	**Total sample N=343**	**Perceive financial burden (n=180)**	**Do not perceive financial burden (n=163)**	**P-value, t or X^2**
Specialty of care				**$^aX^2(2)=9.66^{**}$**
Primary care and specialist	33% (113)	39% (70)	27% (43)	
Primary care only	59% (200)	50% (91)	67% (109)	
Specialist only	6% (21)	8% (14)	4% (7)	
No doctor	2% (8)	3% (5)	2% (3)	
Years since asthma diagnosis (Mean, (SD))	18.01 (14.77)	19.22 (15.03)	16.66 (14.39)	t=-1.57, *NS*
Frequency of symptoms				$X^2(2)=3.14$, *NS*
<2 days per week	61% (210)	57% (103)	66% (107)	
≥ 3 days per week	28% (95)	32% (57)	23% (38)	
Throughout the day	11% (38)	11% (20)	11% (18)	
Asthma control				**$X^2(2)=7.42^{*}$**
Well controlled	30% (101)	23% (42)	36% (59)	
Not well controlled	31% (107)	32% (58)	30% (49)	
Very poorly controlled	39% (135)	45% (80)	34% (55)	
Asthma medications				$^bX^2(2)=0.60$, *NS*
Controller and rescue	70% (238)	71% (126)	70% (112)	
Controller only	4% (13)	4% (8)	3% (5)	
Rescue only	19% (64)	18% (32)	20% (32)	
Allergy only	1% (1)	1% (1)	0% (0)	
Allergy and rescue only	3% (11)	4% (7)	3% (4)	
Leukotriene modifier and rescue	2% (8)	1% (2)	4% (6)	
Leukotriene modifier only	1% (1)	1% (1)	0% (0)	
Total number of medications (Mean, (SD))	5.32 (2.88)	5.51 (3.04)	5.11 (2.70)	t=-1.30, *NS*
Total number of other chronic conditions (Mean, (SD))	3.65 (2.57)	3.71 (2.63)	3.58 (2.52)	t=-0.44, *NS*

Chi-square tests were performed on clinical variables of interest to identify differences between the groups. NS= not significant. Level of significance reported as (p-value): *p<.05, **p<.01, ***p<.001.

a. Due to low cell count, chi-square test is based on the associations between primary care and specialist, primary care only, and specialist only.
b. Due to low cell count, chi-square test is based on the associations controller and rescue, controller only, and rescue only.

Qualitative sample characteristics

Table 4.3 describes economic and demographic characteristics of participants from the focus groups (n=14) and in-depth interviews (n=25). For the focus groups, the mean age of participants in the partial/no insurance group was 49.75 years (SD=10.57), and 41.83 years (SD=15.07) in the full insurance group. Twenty-five percent of participants in the partial/no insurance group and 17% in the full insurance group had three or more individuals in the household. Seventy-five percent of participants in the partial/no insurance group and 33% of participants in the full insurance had an educational attainment of college and above. In the partial/no insurance group, 50% of participants had an annual household income less than $40,000, whereas 100% of participants in the full insurance group reported this level of income. In the partial/no insurance group, 100% reported having private insurance, whereas in the full insurance group, 20% had Medicare and supplemental coverage, 60% had Medicaid, and 20% had other government insurance. Mean years since asthma diagnosis was 12.62 years (SD=11.72) for the partial/no insurance group and 15.66 years (SD=11.46) for the full insurance group. Mean number of other chronic conditions was 1.87 (SD=1.64) for the partial/no insurance group and 2.33 (SD=1.75) for the full insurance group. For the partial/no insurance group, mean out-of-pocket expenses was $207 (SD=284.56) and $30 (SD=36) for the full insurance group. Perception of financial burden was evident for 50% of the partial/no insurance group and 100% for the full insurance group. Eighty-seven percent of the partial/no insurance group reported a preference for communication and 50% reported actually discussing cost with their clinician all of the time. In the full insurance group, 100% of participants reported a preference for communication, and 33% reported actually discussing cost with their clinician all of the time.

For in-depth interviews, the mean age of participants was 51.48 years (SD=10.58), 84% were heads of their household, and 16% had three or more individuals living in their household. Twenty-eight percent had an educational attainment of college and above, and 64% had an annual household income of less than $40,000. Thirty-six percent had private insurance coverage, while 24% had Medicare and supplemental coverage, and 40% had Medicaid. The mean years since asthma diagnosis was 19.41 years (15.80), mean number of other chronic conditions was 5.8 (SD=2.75), and mean total out-of-pocket expenses was $85.90 (SD=211.20). Twenty-four percent perceived financial burden, 12% preferred to discuss cost with their clinician, and 48% reported actually discussing cost with their clinician all of the time.

Components of asthma management perceived as financially burdensome

The results that follow address one aim of this study to describe aspects of asthma management perceived as burdensome. Figure 4.3 provides summary statistics of specific elements of asthma management perceived as financially burdensome. More participants attributed their perceptions of burden to quick-relief medication (28% vs. 17%), and long-term controller medications (37% vs. 11%), compared to those who did not perceive medicines as burdensome.

Qualitative information from focus groups provided context for what financial burden means to individuals when they appraise their own life situations in the context of their asthma. Participants from the focus groups described asthma therapies, environmental control, lost work time, urgent care use, and several other aspects of management as burdensome.

Table 4.3: Characteristics of women who participated in focus groups and in-depth interviews.

Variable	[a]Partial/no insurance Focus group % (n=8)	[b]Full insurance focus group % (n=6)	In-depth interviews % (n=25)
Age (mean, SD)	49.75 (10.57)	41.83 (15.07)	51.48 (10.58)
Head of household (% yes)	86%	83%	84%
Number of individuals in the household			
1	25%	66%	40%
2	50%	17%	44%
3	0	17%	12%
4 and more	25%	0	4%
Educational attainment			
High school /GED or less	25%	17%	24%
Some college, associate's degree, or vocational school	0	50%	48%
College or above	75%	33%	28%
Household income			
<$20,000	25%	50%	56%
$20,001 - $40,000	25%	50%	8%
$40,001 - $60,000	25%	0	20%
>$60,001	25%	0	16%
Health insurance			
No insurance	0	0	0%
Private	100%	0	36%
Medicare only	0	0	0%
Medicare + supplemental coverage	0	20%	24%
Medicaid only	0	60%	40%
Other government	0	20%	0%
Total out-of-pocket expenses (mean, SD)	$207 (284.56)	$30 (36)	$85.90 (211.20)
(Range)	$0-$640	$0-$72	$0-$1,000
Years since asthma diagnosis (Mean, (SD))	12.62 (11.72)	15.66 (11.46)	19.41 (15.80)

Table 4.3: Continued

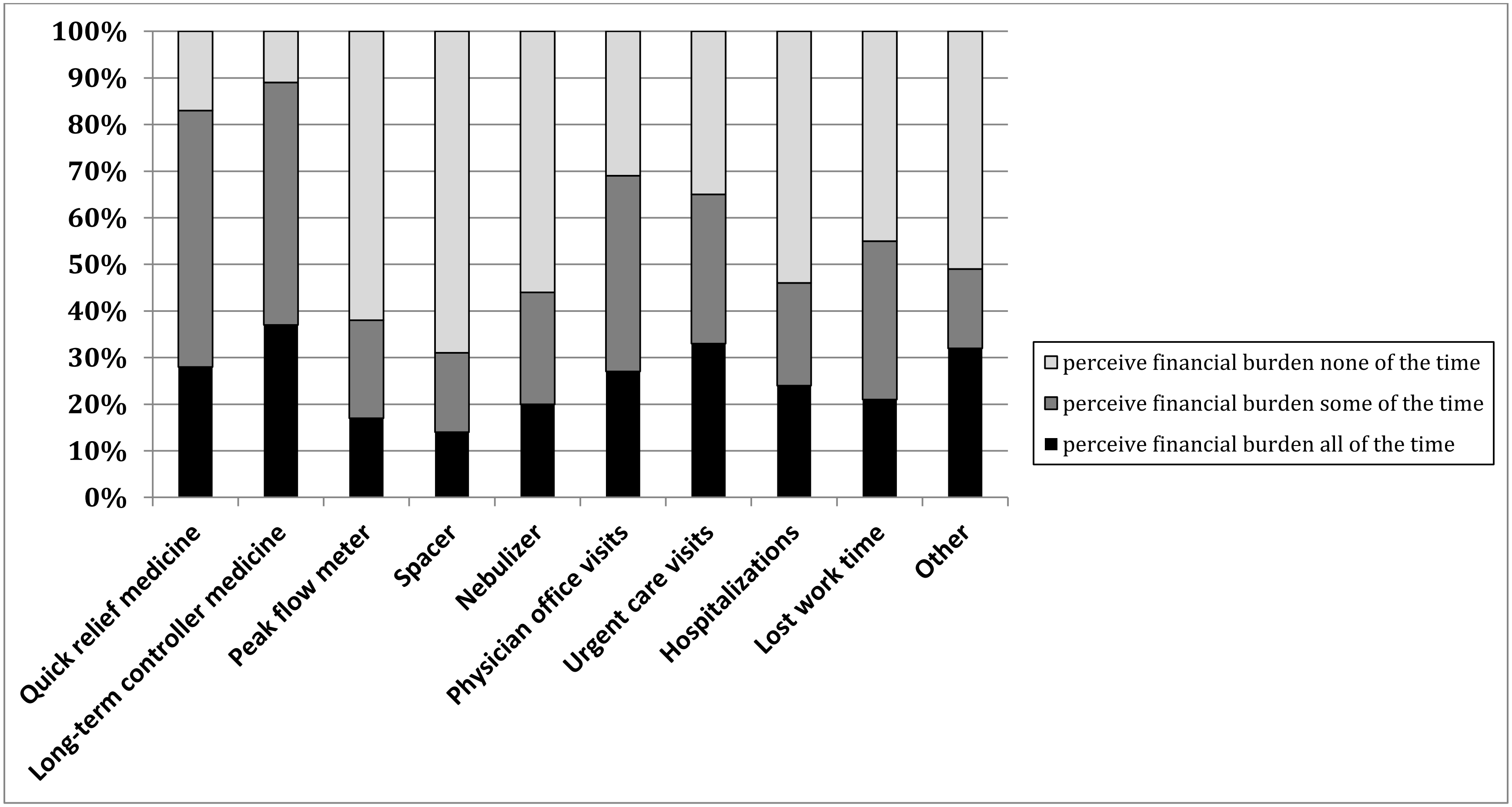
Variable	**^{a}Partial/no insurance Focus group % (n=8)**	**^{b}Full insurance focus group % (n=6)**	**In-depth interviews % (n=25)**
Total number of other chronic conditions (Mean, (SD))	1.87 (1.64)	2.33 (1.75)	5.8 (2.75)
Perception of financial burden (% yes)	50%	100%	24%
Preference for cost of care-related communication with provider			
Not at all important	13%	0	52%
Somewhat important	0	0	36%
Important	87%	100%	12%
Frequency of cost of care-related communication with provider			
None of the time	0	17%	24%
Some of the time	50%	50%	28%
All of the time	50%	33%	48%

a. Partial insurance= private, no insurance, Medicare only.
b. Full insurance= Medicaid, Medicare and supplemental coverage, other government insurance.

Asthma therapies

Among aspects of asthma management perceived as financially burdensome, asthma therapies was a common theme and was mentioned most often. There was consensus among individuals in both the partial/no and full insurance groups concerning the fact that many asthma medications do not come in generic form, therefore the price in terms of co-pays and total amount they are spending out-of-pocket each month is high due to brand name prescriptions.

Figure 4.3: Perceptions of financial burden with specific elements of asthma management among individuals who reported global financial burden with their asthma management (n=180).



These out-of-pocket expenses ranged from $1-$5 for co-pays to spending nearly $6,000 out-of-pocket just on medications in one year. A middle-aged participants in the full insurance group who previously had a private, individual health insurance plan (partial insurance) described how her out-of-pocket expenses for medicines accumulated:

> "--$389. 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. And when you don't have insurance or you have, in my experience, as a sole practitioner, I had individual 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, $5,720. Out of pocket, to breathe.

In addition to asthma therapies, themes emerged from focus groups around environmental control, lost work time, and asthma-related urgent care use being particularly burdensome.

Environmental control

Focus group participants expressed that environmental maintenance and modification to prevent asthma triggers was expensive and not often covered by health insurance. These observations were most common among individuals with partial/no insurance. They noted particular examples such as central air conditioning, air filters, and purchasing only certain kinds of cleaning products. One woman in the partial/no insurance group noted that air filters are not covered by her insurance:

> "Insurance don't cover it. A filter to clean the air in the house. It's pretty expensive, but it really helps with cleaning the air that I'm breathing in."

A few women in the partial/no insurance group noted the lack of insurance coverage available to assist with implementing environmental changes to their home in order to help control their asthma made out-of-pocket expenses so great that moving became the only option.

Lost work time

Several participants in the partial/no insurance focus group reported lost work time due to asthma exacerbations, leading to missed opportunities for earned income. They expressed concern with needing to make decisions about using sick days, and inability to maintain a stable job. An employed participant was aware of the financial consequences of using sick days allotted by her employer during times when her asthma was not under control:

> "So, you can't afford to be out of work sick and exhaust your sick days because once you exhaust your sick days, you're borrowing sick time."

A middle-aged employed participants from the full insurance group noted that hospital visits require at-home recovery and going to work becomes difficult:

> "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 – ain't no, 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."

Urgent care use

Focus group participants expressed that urgent care use for asthma was a source of high out-of-pocket expenses for them. There was consensus regarding these sentiments, especially in the partial/no insurance group. They noted that urgent care facilities are cheaper than emergency rooms, but were not always close in proximity in the event of emergencies. Participants described the co-pay for an emergency department visit as "such a waste" when the treatment administered to them is similar or equivalent to the rescue therapies they have been prescribed. They also noted that the cost associated with having an ambulance take them to the hospital was several hundred dollars out-of-pocket in the event of an emergency. One participant in the partial/no insurance group noted that the high costs and method of billing associated with emergency departments prevented them from seeking treatment at a hospital in emergency situations due to past experiences:

> "It's asthma, and you need medication to breathe, if you don't have your medication, and your only option is the emergency room, now in the emergency room, in the past they wouldn't say, "you know, you owe, this is your bill. How would you like to pay for this?" Which they do now, in the emergency room, they ask you, 2:00 in the morning, after you breathing, well, they want to know how you gonna pay this emergency bill. They don't bill you. They'll ask at the emergency room. So, that's another fear, and a lot of people that have asthma won't go to the hospital. Because they're afraid of the bill from the emergency room—they can't afford it. An average bill for going to the emergency room with an asthma attack is $1200."

Other

Other aspects of asthma management perceived as financially burdensome noted by the partial/no insurance focus group included the medication costs of managing other chronic conditions with asthma and repeated tests during initial diagnosis of asthma. A middle-aged participant in the full insurance group noted that cheaper products exacerbate illness or do not achieve the same level of efficacy as more expensive, brand name products for asthma management, thus leaving her no choice but to purchase costlier products:

> "And you know what else I can't do, I cannot use cheap stuff, like the dollar store stuff, like soap powder and soap and stuff like that. I don't know what it is, or what they put in it. It just breaks me out. I just, I just, I have to have the expensive stuff. The expensive stuff works for me and I carry, I mean, in my pockets, and I don't even get that much money."

In the full insurance group, individuals with Medicaid described the burden of indirect costs associated with transitioning to a public insurance program from private health insurance in the current economic climate. One woman in this group who recently transitioned to Medicaid from a private insurance plan noted:

> "Gas is expensive. I've got to – I've never had to deal, I've never – I worked all my life. I never had, I never was on Medicaid. I've always worked. I was married, me and my husband always worked. I never made, we made too much money to have, have food stamps and medications and stuff. Always had a private plan. You know, and dental plans and stuff like that. 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 Ypsi [Ypsilanti] and drive back. It's just hard, you know, dealing with all of that."

Coping with financial burden

Focus group participants most commonly described perceptions of financial burden with a coping response. Participants expressed high self-efficacy with managing their asthma even in the face of hardship. One woman with Medicare and supplemental insurance in the full insurance group who had multiple chronic conditions noted:

> "But it's been a – I'm blessed. I can say that much. Like I been empowered with everything that's concerning asthma because I've been dealing with them for so long."

Another middle-aged woman in the full insurance group described the support of her social network as a means of buffering financial stress:

> "I'm not rich. You know that. But I don't know, I can't say I have financial stress. I mean, it's – things I would like to just go out and get, just like that, but I always have what I need and sometimes more than what I need. And any times my sons think I want or need anything, they provide it without me asking. Or the Lord. You know, so, I can't complain."

Several participants in both the full and partial/no insurance focus groups mentioned that they stockpile medicines and plan ahead for times when they themselves or a family member may be in need of medication but may not have the means to purchase it. One woman in the partial/no insurance group 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."

In the full insurance group, a middle-aged woman with grown children also described stockpiling because her children often struggled with maintaining their own continuous insurance coverage:

> "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. 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 work. Well, now she does because she got that – you know, they give it to you at [hospital system] as soon as you start the job. So, that was a blessing because she 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."

A few participants in both the partial/no and full insurance groups mentioned prayer as a means of coping with financial stress. A middle-aged woman with Medicaid in the full insurance group 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. As long as they get something on them, that's all I'm worried about."

Others in both focus groups described their current situation as better than the alternative (e.g. not breathing, paying full price for medications), and accept the status quo as indicated by phrases such as "grin and bear it", or "it is what it is." A middle-aged woman in the full insurance group described living with financial burden as a bearable situation compared to not being able to breathe from uncontrolled asthma:

> "um, it is a burden. It's tiring, it's irritating. But you know what? I don't complain much because the alternative is not breathing and not being alive. So, even on days like Monday when it was wet and humid and moisture and I had to wear a mask and it was just irritating. It was a bad hair day, breathing day, just a bad day, all the way around. I still don't complain, even having to take, uh, Prednisone and when your ankles swell up to ten times the size and it's just, everything just looks ugly, I don't complain too much about it because he alternative is not breathing. So, I just roll with it. And been rolling with it now for about six or seven years. So, I don't – I – and like I said, I know it is just, it's awful. It is really awful, but you're breathing and you're breathing and walking and that's a good thing. That's a good thing. So, I always keep that in mind, even when I have to have a mask on, and I'm walking around with a portable nebulizer everywhere I go. I have it in the car all the time. Um, but I'd rather be doing that than the alternative."

In the partial/no insurance group, a woman with private insurance expressed that her co-pay was a better situation for her than the full cost of the medicine:

> "So then I look at it in a positive way. Um, this copay is $35, but I'm glad I'm not paying the whole thing."

In the full insurance group, participants described medical bills as a source of stress that triggers their asthma. As a result, they reported having learned to not worry about the financial burden for the sake of keeping their asthma under control. A recent college graduate noted:

> "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 $2,000 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. That's how I, like, have taken, like, the approach right now. Like, I just – I can pay my rent. I can pay this bill. I can pay that bill. I can't pay you right now. And I'm not gonna let myself get over worked up. You can't get upset. It doesn't help you. You just end up back in the hospital. That stress will get you."

Bivariate relationships between economic and demographic characteristics and perceptions of financial burden

Table 4.1 shows economic and demographic factors associated with perceptions of financial burden. Economic factors significantly associated with burden included: 1) private and other government health insurance ($X^2(5) = 14.24$; $p<0.01$), and 2) more out-of-pocket expenses ($t=-4.74$, $p<0.001$). Individuals who perceived burden had three times the mean out-pocket expenses of those who did not report burden.

Although significant associations between perceptions of financial burden and educational attainment were not found, qualitative examinations from focus groups revealed that participants consider their education an important resource for anticipating cost-related challenges. One participant with partial insurance described her degree as providing her with skills that were beneficial in understanding options when faced with challenges with out-of-pocket health care expenses:

> "Wouldn't call myself an expert but, um, I have a bachelors in health service administration, and one of the things that we were taught in the class, that that was an option, that you can negotiate the cost of your health care, especially when you don't have insurance. Now, not so much with the pharmacy, but with your own, private physician."

Other participants with full insurance alluded to educational attainment as helpful in an unpredictable economic climate:

> "See, I'm the type of person, I don't just live in the day. I think about later on, down the line. And that's why I kind of like stay in school."

In contrast, another participant in her early 20's with full insurance reported challenges with opportunities for education due to her asthma:

> "I got kicked out of school. I was going to [school name] School, and you can only miss seven days. Two of the days they sent me home 30 minutes early because I was having an asthma attack in class. Those two days counted. Then I actually had the ambulance come up to get me from that, and those counted. So, all together it was seven, and I got kicked out. Very disappointing. Very. I tried to go back, and they wouldn't take me obviously. Too many attacks."

Bivariate relationships between clinical characteristics and perceptions of financial burden

Table 4.2 describes clinical factors associated with perceptions of financial burden. Clinical factors significantly associated with burden were 1) seeing a primary care and specialist ($X^2(2) = 9.66$; $p<0.05$), and 2) worse asthma control ($X^2(2) = 7.42$; $p<0.05$).

Path analytic results

A path model that allowed for the estimation of multiple equations simultaneously was computed, so that associations between multiple predictor and outcome variables could be assessed in the same model. The path analytic results address the second aim of this study to explore indirect relationships between patients' clinical and demographic characteristics and perceptions of financial burden. The results that follow first describe direct relationships in the model and then address the study hypotheses: 1) the relationship between demographic factors and perception of financial burden will be mediated through household income, health insurance, and out-of-pocket expenses, 2) the relationship between clinical factors and perception of financial burden will be mediated through out-of-pocket expenses, and 3) Health insurance will have a moderating effect on the relationships in hypotheses 1 and 2.

Direct effects in the path model of patient factors on perception of financial burden and economic mediators

The final fit of the model in Figure 4.2 was based on recommended values of several criteria recommended from the literature. The fit criteria based on the RMSEA suggested that model’s correspondence to the data was good (X^2=87.88, df=43, p<0.001; CFI= 0.86, RMSEA= 0.05, 90% CI: 0.04 to 0.075; WRMR=1.14) (MacCallum, Browne & Sugawara, 1996). Good fit implies that a model is plausible. However, no set of fit statistics are definitive or provide a gold standard whether to retain or reject a model (Kline, 2011). Kenny (2012) suggests that the CFI should not be computed if the RMSEA of the null model is less than 0.158 or otherwise one will obtain too small a value of the CFI (Kenny, 2012). CFI is sensitive to the number of the parameters in the model (Kenny, 2012), which may be one plausible reason why the CFI was observed to be slightly below the recommended threshold in this study, but other fit statistics such as the RMSEA suggested that the model fit was good. The model was theoretically sound and provided a vehicle for testing the hypotheses of this study. The model serves as an approximation of hypothesized processes.

Forty-one percent of the variance in the model was explained by out-of-pocket expenses, while 52% was explained by household income , 53% explained by health insurance, and 22% of the variance in the model explained by perception of financial burden.

Table 4.4 shows direct effects in the analytic model of patient factors on perception of financial burden and economic mediators. To ease the comparison of coefficients, standardized coefficients for the measurement model are provided, in addition to the significance associated with the unstandardized estimate: (unstandardized estimate (standard error) standardized estimate) (Kline, 2011). Participants who reported more out-of-pocket expenses were more likely to perceive financial burden compared to participants with fewer out-of-pocket expenses (β=0.435 (SE=0.096) 0.503, p<0.001). A significant, direct relationship was not found for household income and perceptions of financial burden.

Table 4.4: Direct effects in the path model of clinical and demographic factors on perception of financial burden and economic mediators.

	Out-of-pocket expenses	**Household income**	**Health insurance (Full insurance)**	**Perception of financial burden**
Predictors	Unst. (SE) Stn.	Unst. (SE) Stn.	Unst. (SE) Stn.	Unst. (SE) Stn.
CLINICAL FACTORS				
Multimorbidity	-0.153** (0.061) -0.302			
Asthma control				
Not Well Controlled	0.230 (0.239) 0.081			
Poorly Controlled	0.121(0.263) 0.045			
Frequency of asthma symptoms				
Three or more days per week	0.092 (0.217) 0.031			
Daily	0.163 (0.312) 0.040			
Years since diagnosis	0.002 (0.006) 0.017			
Total number of medications	0.144** (0.057) 0.314			
ECONOMIC AND DEMOGRAPHIC FACTORS				
Age		0.017** (0.006) 0.171	-0.020* (0.009) -0.204	
Marital status (Married)		1.09** (0.204) 0.343		
Employment status				
Part time		0.704** (0.225) 0.216		
Full time		1.283*** (0.213) 0.436		
Number of individuals in household		-0.016 (0.078) -0.013		
Educational attainment				
Some college		0.816*** (0.217) 0.283		
College and above		1.53*** (0.227) 0.501		

Table 4.4: Continued

	Out-of-pocket expenses	**Household income**	**Health insurance (Full insurance)**	**Perception of financial burden**
Predictors	Unst. (SE) Stn.	Unst. (SE) Stn.	Unst. (SE) Stn.	Unst. (SE) Stn.
Household income			-0.674*** (0.148) -0.665	-0.088 (0.085) -0.113
Health insurance (Full insurance)	-0.529*** (0.102) -0.591			
Out-of-pocket expenses				0.435*** (0.096) 0.503

P<0.05*, P<0.01**, P<0.001***; Unst.= unstandardized estimate, SE= standard error, Stn.= standardized estimate. Reference categories- Asthma control- well controlled, Frequency of asthma symptoms- 2 days or less, Marital status- single, Employment status- unemployed, Educational attainment- high school or less/GED, Health insurance- partial/no insurance. Partial insurance= private, no insurance, Medicare only. Full insurance= Medicaid, Medicare and supplemental coverage, other government insurance.

Household income was directly related to health insurance: compared to individuals with more income, those with less household income were more likely to have full insurance coverage (e.g. Medicare and supplemental coverage, Medicaid, other government sponsored insurance) (β= -0.674 (SE=0.148) -0.665, $p<0.001$). Compared to individuals with partial health insurance coverage (e.g. private health insurance, Medicare only, and no insurance), individuals with full insurance coverage had fewer out-of-pocket expenses (β= -0.529 (SE=0.102) -0.591, $p<0.001$).

Clinical factors directly associated with out-of-pocket expenses included 1) multimorbidity: participants who reported more chronic conditions had fewer out-of-pocket expenses (β= -0.153 (SE=0.061) -0.302, $p<0.01$), and 2) total number of medications: participants with more medications had more out-of-pocket expenses (β=0.144 (SE=0.057) 0.314, $p<0.01$).

Indirect effects in the path model of clinical and demographic factors on perception of financial burden

Table 4.5 shows indirect effects in the path model of demographic and clinical factors on perception of financial burden. Standardized estimates with bootstrapped standard errors are reported here. Out-of-pocket expenses mediated the relationship between type of health insurance (full insurance) and perceptions of financial burden. Having full insurance coverage indicated fewer out-of-pocket expenses, and fewer out-of-pocket expenses indicated less frequent perceptions of financial burden (β= -0.297 (SE=0.083), $p<0.001$).

Table 4.5: Indirect effects in the path model of clinical and demographic factors on perception of financial burden.

Path	Unstandardized (S.E.)	Standardized (S.E.)	Sum of indirect, Unst. (S.E)	Sum of indirect, Stn. (S.E.)
CLINICAL FACTORS				
Multimorbidity → out-of-pocket expenses → perception of financial burden	-0.067 (0.027)**	-0.152 (0.062)**		
Not well controlled asthma → out-of-pocket expenses → perception of financial burden	0.100 (0.112)	0.041 (0.045)		
Poorly controlled asthma→ out-of-pocket expenses → perception of financial burden	0.053 (0.126)	0.023 (0.054)		
Three or more days of symptoms→ out-of-pocket expenses → perception of financial burden	0.040 (0.101)	0.016 (0.039)		
Daily symptoms → out-of-pocket expenses → perception of financial burden	0.071 (0.140)	0.020 (0.039)		
Years since diagnosis → out-of-pocket expenses → perception of financial burden	0.001 (0.003)	0.009 (0.037)		
Total medications → out-of-pocket expenses → perception of financial burden	0.063 (0.025)**	0.158 (0.062)**		
ECONOMIC AND DEMOGRAPHIC FACTORS				
Age → health insurance (Full) → out-of-pocket expenses → perception of financial burden	0.005 (0.003)	0.061 (0.034)		
Age → household income → Perceptions of burden	-0.001 (0.002)	-0.019 (0.022)		
Health insurance (Full) → out-of-pocket expenses → perception of financial burden	-0.230 (0.066)***	-0.297 (0.083)***		

Table 4.5: Continued

Path	Unstandardized (S.E.)	Standardized (S.E.)	Sum of indirect, Unst. (S.E)	Sum of indirect, Stn. (S.E.)
Household income → health insurance (Full) → out-of-pocket expenses → perception of financial burden	0.155 (0.048)***	0.198 (0.061)***		
Marital status (Married) → perception of financial burden			0.073 (0.074)	0.029 (0.029)
Marital status (Married) → household income → health insurance (Full) → out-of-pocket expenses → perception of financial burden	0.169 (0.066)**	0.068 (0.026)**		
Marital status (Married) → household income → perception of financial burden	-0.096 (0.100)	-0.039 (0.040)		
Part time employment → perception of financial burden			0.047 (0.053)	0.018 (0.021)
Part time employment → household income → health insurance (Full) → out-of-pocket expenses → perception of financial burden	0.109 (0.055)*	0.043 (0.021)*		
Part time employment → household income → perception of financial burden	-0.062 (0.066)	-0.024 (0.026)		
Full time employment → perception of financial burden			0.086 (0.091)	0.037 (0.039)
Full time employment → household income → health insurance (Full) →out-of-pocket expenses → perception of financial burden	0.199 (0.074)**	0.086 (0.031)**		
Full time employment → household income → perception of financial burden	-0.113 (0.115)	-0.049 (0.049)		

Table 4.5: Continued

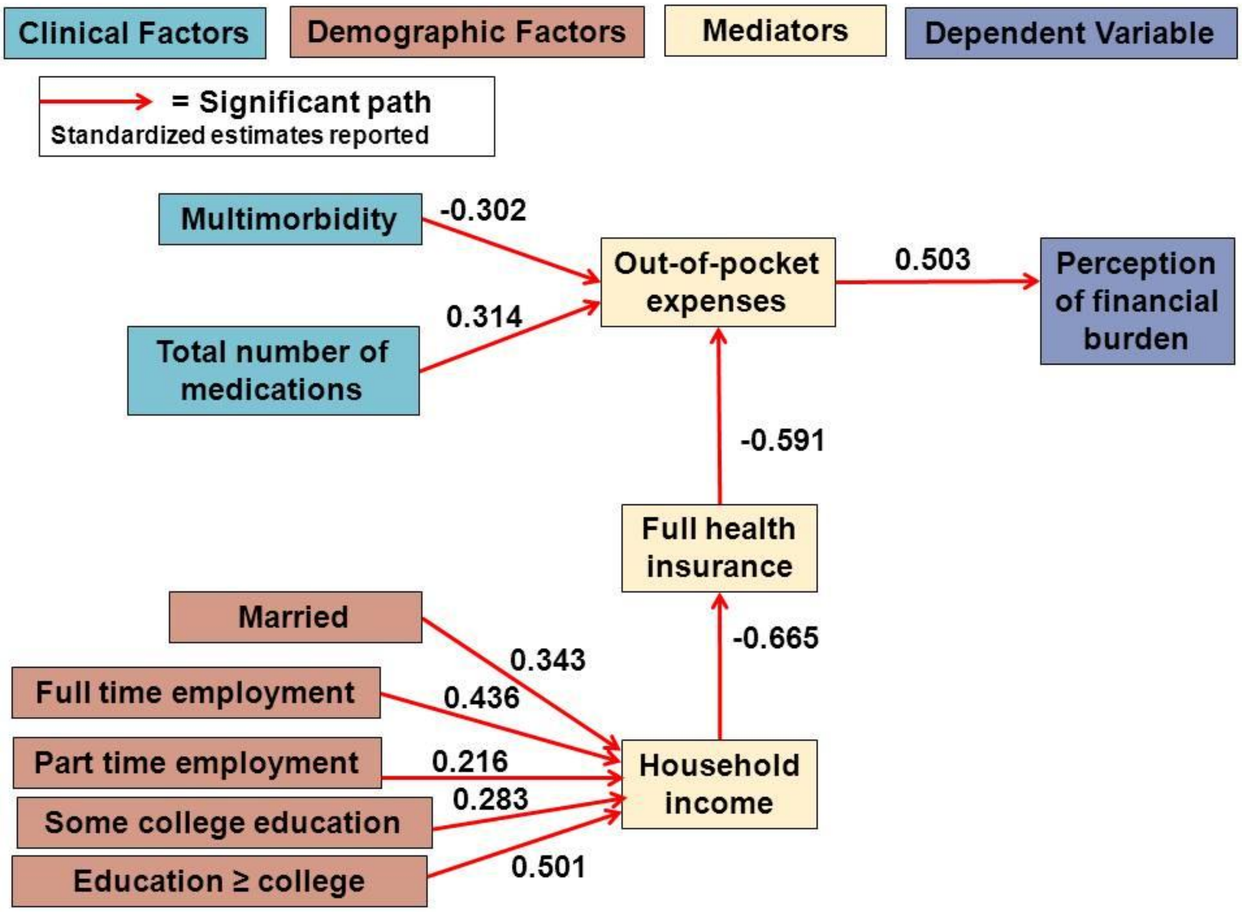
Path	Unstandardized (S.E.)	Standardized (S.E.)	Sum of iindirect, Unst. (S.E)	Sum of indirect, Stn. (S.E.)
Number of individuals in the household → perception of financial burden			-0.001 (0.008)	-0.001 (0.008)
Number of individuals in the household → household income → health insurance (Full) → out-of-pocket expenses → perception of financial burden	-0.003 (0.014)	-0.003 (0.014)		
Number of individuals in the household → household income → perception of financial burden	0.001 (0.010)	0.001 (0.010)		
Some college → perception of financial burden			0.055 (0.065)	0.024 (0.028)
Some college → household income → health insurance (Full) → out-of-pocket expenses → perception of financial burden	0.127 (0.056)*	0.056 (0.024)*		
Some college → household income → perception of financial burden	-0.072 (0.075)	-0.032 (0.033)		
College and above → perception of financial burden			0.102 (0.114)	0.043 (0.047)
College and above → household income → health insurance (Full) →out-of-pocket expenses → perception of financial burden	0.238 (0.085)**	0.099 (0.034)**		
College and above → household income → perception of financial burden	-0.135 (0.135)	-0.056 (0.056)		

P<0.05*, P<0.01**, P<0.001***; Unst.= unstandardized estimates, SE= standard error, Stn.= standardized estimate; Reference categories- Asthma control- well controlled, Frequency of asthma symptoms- 2 days or less, Marital status- single, Employment status- unemployed, Educational attainment- high school or less/GED, Health insurance- partial/no insurance. Partial insurance= private, no insurance, Medicare only. Full insurance= Medicaid, Medicare and supplemental coverage, other government insurance.

Type of health insurance and out-of-pocket expenses mediated the pathway between household income and perceptions of financial burden. More income indicated a higher likelihood of having partial/no insurance, partial/no health insurance indicated more out-of-pocket expenses, and more out-of-pocket expenses indicated more frequent perceptions of financial burden (β= 0.198 (SE=0.061), p<0.001).

The results also partially supported hypothesis 1 for marital status, employment status, and educational attainment. Household income, type of health insurance, and out-of-pocket expenses mediated the pathway between perceptions of financial burden and 1) married, 2) some college and college education and above, and 3) part time and full time employment. Being married as opposed to single indicated more income, more income indicated a higher likelihood of having partial/no health insurance, partial/no health insurance indicated more out-of-pocket expenses, and more out-of-pocket expenses indicated more frequent perceptions of financial burden (β= 0.068 (SE=0.026), p<0.01). Some college (β= 0.056 (SE=0.024), p<0.05) and college education and above β= 0.099 (SE=0.034), p<0.01) as opposed to less than a high school education indicated more income, more income indicated a higher likelihood of having partial/no health insurance, partial/no health insurance indicated more out-of-pocket expenses, and more out-of-pocket expenses indicated more frequent perceptions of financial burden. Part time (β= 0.043 (SE=0.021), p<0.05) and full time employment (β= 0.086 (SE=0.031), p<0.01) as opposed to no employment indicated more income, more income indicated a higher likelihood of having partial/no health insurance, partial/no health insurance indicated more out-of-pocket expenses, and more out-of-pocket expenses indicated more frequent perceptions of financial burden. All significant paths with standardized estimates are seen in Figure 4.4.

Figure 4.4: Analytic model depicting estimates of relationships between clinical and demographic factors and perception of financial burden.



In considering the qualitative findings concerning employment, the full insurance group revealed that lost employment opportunities from uncontrolled asthma has had a prolonged impact on maintaining stable employment for some individuals. A middle-aged participant noted:

> "I really want to be successful, myself, you know, and you know, I want to work. You know? And it has been a very challenged thing for me. I haven't been able to work because I was – through my life I had several jobs, and I was losing them because I'm always in the hospital, so I couldn't work."

A young adult in the full insurance group expressed that asthma is already having an impact on her ability to sustain employment.

> "And I can't stay at a job because I'm always getting sick. So, how am I making anything happen?"

The results that follow address what clinical factors are indirectly associated with perception of financial burden. The results partially supported hypothesis 2 for multimorbidity and total number of medications: out-of-pocket expenses mediated the relationship between perceptions of burden and 1) multimorbidity, and 2) total number of medications. More chronic conditions indicated fewer out-of-pocket expenses, and fewer out-of-pocket expenses indicated less frequent perceptions of financial burden ($\beta = -0.152$ ($SE=0.062$), $p<0.01$). More medications indicated more out-of-pocket expenses, and more out-of-pocket expenses indicated more frequent perceptions of financial burden ($\beta = 0.158$ ($SE=0.062$), $p<0.01$).

Many participants in the partial/no insurance group with private insurance plans experienced variability in terms of which asthma therapies were covered on their formulary. They described uncovered brands of medicines contributing to high out-of-pocket costs. Participants described their out-of-pocket costs as "ridiculous", "outrageous", "very expensive", "costly", "such a waste", "these people are in the wrong business." Participants who were prescribed a nebulizer described this therapy to be particularly expensive. Others described the number of inhalers they were prescribed, and the co-pay for each inhaler contributing to their high out-of-pocket costs. One woman in the partial/no insurance group noted the high costs of her prescribed medicines because they were not covered on her formulary:

> “But the inhalers are what costs so much. Two inhalers every month. One was $240, the other one was, like, $380. And insurance won’t cover it.”

Another participant in the partial/no insurance group described the various co-pays with her medicines and how they contribute to her out-of-pocket costs in a year:

> “And some of them are $28 a piece. Some are $12. I have some that’s seven, some that’s five, so I usually average about $3,000 out of pocket a year for my meds. That’s strictly meds.”

Differences by full versus partial/no health insurance coverage

Economic, demographic, and clinical differences between individuals with full versus partial/no health insurance are shown in Tables 4.6 and 4.7 respectively. Demographic and economic differences between individuals with full versus partial/no insurance were evident for marital status, head of household, educational attainment, employment status, household income, and out-of-pocket expenses. Clinical differences between individuals with full versus partial/no insurance were evident for specialty of the care providing clinician, frequency of asthma symptoms, asthma control, total number of medications, and multimorbidity.

Table 4.6: Economic and demographic characteristics of participants of individuals with full versus partial/no insurance.

Variable	Total sample N=343	[a]Partial/no insurance (n=167)	[b]Full insurance (n=176)	t or X^2
Age (mean, SD)	43.11 (14.82)	43.51 (12.29)	42.73 (16.89)	t=0.49, *NS*
Marital status (% Married)	29% (100)	37% (61)	22% (39)	**X^2(1)=8.78****
Head of household (% yes)	67% (230)	61% (102)	73% (128)	**X^2(1)=5.30***
Number of individuals in the household				X^2(3)=0.315, *NS*
1	38% (132)	38% (63)	39% (69)	
2	27% (92)	28% (47)	26% (45)	
3	15% (51)	14% (24)	15% (27)	
4 and more	20% (68)	20% (33)	20% (35)	
Educational attainment				**X^2(2)=36.04*****
High school /GED or less	21% (70)	8% (14)	32% (56)	
Some college, associate’s degree, or vocational school	47% (162)	48% (80)	47% (82)	
Employment status				**X^2(2)=69.82*****
Part-time	26% (87)	59 % (94)	25% (43)	
Full-time	39% (131)	28% (44)	21% (37)	
No employment	35% (114)	13% (21)	54% (93)	
Household income				**X^2(3)=92.17*****
<$20,000	42% (137)	16% (25)	66% (112)	
$20,001 - $40,000	24% (79)	29% (45)	20% (34)	
$40,001 - $60,000	18% (57)	27% (4)	9% (16)	
>$60,001	16% (52)	28% (44)	5% (8)	
Out-of-pocket expenses (mean, SD)	$163.27 (308.27)	$235.68 (364.77)	$95.39 (224.68)	**t=4.24*****
(Range)	$0-$2,840	$0-$2,840	$0-$2,000	

Student’s t-test and chi-square tests were performed on demographic variables of interest to identify differences between the groups. NS= not significant. Level of significance reported as (p-value): *p<.05, **p<.01, ***p<.001.

a. Partial insurance= private, no insurance, Medicare only.
b. Full insurance= Medicaid, Medicare and supplemental coverage, other government insurance.

Table 4.7: Clinical characteristics of participants with full vs. partial/no insurance.

Variable	Total sample N=343	[a]Partial/no insurance (n=167)	[b]Full insurance (n=176)	P-value, t or X^2
Specialty of care				**[c]X^2(2)=22.12*****
Primary care and specialist	33% (113)	44% (73)	23% (40)	
Primary care only	59% (200)	45% (75)	71% (125)	
Specialist only	6% (21)	8% (13)	4% (8)	
No doctor	2% (8)	3% (5)	2% (3)	
Years since asthma diagnosis (Mean, (SD))	18.01 (14.77)	16.70 (14.24)	19.29 (15.20)	t=-1.59, *NS*
Frequency of symptoms				**X^2(2)=12.34****
<2 days per week	61% (210)	71% (118)	52% (92)	
≥ 3 days per week	28% (95)	21% (36)	34% (59)	
Throughout the day	11% (38)	8% (13)	14% (25)	
Asthma control				**X^2(2)=26.92*****
Well controlled	30% (101)	41% (68)	19% (33)	
Not well controlled	31% (107)	32% (54)	30% (53)	
Very poorly controlled	39% (135)	27% (45)	51% (90)	
Asthma medications				[d]X^2(2)=1.14, *NS*
Controller and rescue	70% (238)	71% (116)	71% (122)	
Controller only	4% (13)	5% (8)	3% (5)	
Rescue only	19% (64)	18% (29)	20% (35)	
Allergy only	1% (1)	1% (1)	0% (0)	
Allergy and rescue only	3% (11)	2% (4)	4% (7)	
Leukotriene modifier and rescue	2% (8)	2% (4)	2% (4)	
Leukotriene modifier only	1% (1)	1% (1)	0% (0)	
Total number of medications (Mean, (SD))	5.32 (2.88)	4.82 (2.60)	5.79 (3.06)	**t=-3.14*****
Total number of other chronic conditions (Mean, (SD))	3.65 (2.57)	3.07 (2.31)	4.19 (2.69)	**t=-4.12*****

Chi-square tests were performed on clinical variables of interest to identify differences between the groups. NS= not significant. Level of significance reported as (p-value): *p<.05, **p<.01, ***p<.001.

a. Partial/no insurance= private, no insurance, Medicare only.
b. Full insurance= Medcaid, Medicare and supplemental coverage, other government insurance.
c. Due to low cell count, chi-square test is based on the associations between primary care and specialist, primary care only, and specialist only.
d. Due to low cell count, chi-square test is based on the associations controller and rescue, controller only, and rescue only.

The results seen in Table 4.8 supported hypothesis 3. Adding the cross-group equality constraints revealed evidence that the relationships of interest in the model varied by health insurance status (ΔX^2 (3) = 21.30, $p<0.001$); overall, strong support was found for health insurance status moderating the relationships between household income, out-pocket expenses, and perceptions of financial burden.

Table 4.8: Difference testing: multiple group model to examine the moderated effects of health insurance (full vs. partial/no coverage*) on the relationships in the path model.

Hypothesis Description	**X^2**	**df**	**RMSEA**	**Models compared**	**ΔX^2 *****	**Δ df**	**p-value**
1. Free Model	76.464	56	0.048	--	--	--	--
2. 3 regression constraints (partially constrained)**	94.756	59	0.062	2 & 1	21.30	3	**<0.001**
3. Fully constrained model	111.957	73	0.058	3 & 2	19.514	14	0.1462

*Full insurance= Medicaid, Medicare and supplemental coverage, other government insurance; Partial/no insurance= private, no insurance, Medicare only.

** 3 constrained paths: 1) household income → Out-of-pocket expenses, 2) household income → perceptions of financial burden, 3) Out-of-pocket expenses → perceptions of financial burden.

***Since the estimator used to compute the models was a mean- and variance adjusted chi-square test statistic that uses a full weight matrix (WLSMV), special procedures were used to calculate differences in chi-square, specifically the difftest procedure in Mplus.

Table 4.9 more closely examines the differences between individuals with full and partial/no insurance with estimates of between-group differences between the effects of household income and out-of-pocket expenses on perceptions of financial burden. To ease the comparison of coefficients, standardized coefficients for the measurement model are provided, in addition to the significance associated with the unstandardized estimate: (unstandardized estimate (standard error) standardized estimate) (Kline, 2011). For the full insurance group, more income was associated with more out-of-pocket expenses ($\beta= 0.301$ (SE=0.089) 0.342, $p<0.001$), whereas this relationship was not observed for the partial/no insurance group. For both the full (β= 0.632 (SE=0.134) 0.577, $p<0.001$) and partial/no insurance groups (β= 0.314 (SE=0.10) 0.326, $p<0.01$), more out-of-pocket expenses was associated with more frequent perceptions of financial burden. All significant paths with standardized estimates are seen in Figure 4.5.

The partially constrained model accounted for less variance among the full insurance group compared to the partial/no insurance group for out-of-pocket expenses (21% for partial/no insurance, 18% for full insurance), household income (45% for partial/no insurance, 36% for full insurance), but more variance for the full insurance group compared to the partial/no insurance group for perceptions of financial burden (15% for partial/no insurance, 32% for full insurance).

Themes from qualitative investigations further justify some commonalities observed with the indirect effect of health insurance on perceptions of financial burden. There was consensus among participants from both focus groups regarding health insurance as a source of uncertainty in having sufficient resources to manage their asthma. One participant with private insurance in the partial/no insurance group described this uncertainty in the context of having coverage in itself:

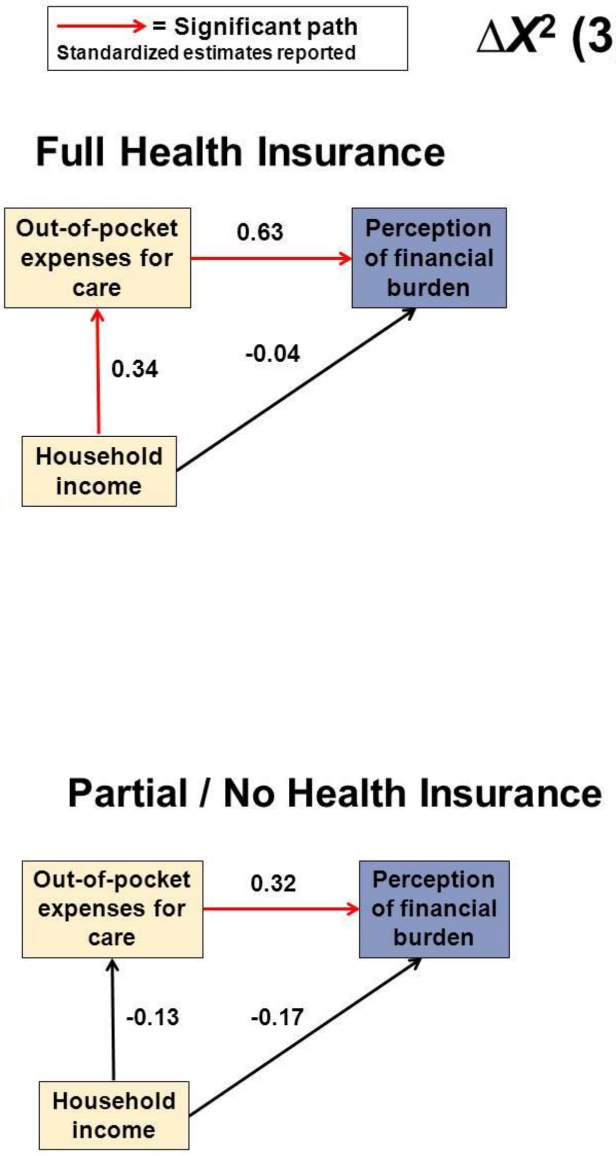
> "It does affect it my asthma. It does because, um, with the changing economy, you never know what's next, what's gonna be cut out that you may have to take full responsibility for what your employers no longer are gonna offer."

Table 4.9: Estimates of between-group differences: multiple group model to examine the moderated effects of health insurance (full vs. partial/no coverage*) on the relationships in the path model.

Hypothesis Description	**Full Insurance**	**Partial/no Insurance**
	Unst. (SE) Stn.	**Unst. (SE) Stn.**
Household income → out-of-pocket expenses	0.301*** (0.089) 0.342	-0.109 (0.085) -0.131
Household income → perceptions of financial burden	-0.045 (0.098) -0.047	-0.144 (0.08) -0.179
Out-of-pocket expenses → perceptions of financial burden	0.632*** (0.134) 0.577	0.314** (0.10) 0.326

Level of significance reported as (p-value): *p<.05, **p<.01, ***p<.001; Unst.= unstandardized estimates, SE= standard error, Stn.= standardized estimate. Partial insurance= private, no insurance, Medicare only. Full insurance= Medicaid, Medicare and supplemental coverage, other government insurance.

Figure 4.5: Estimates of between-group differences: multiple group model to examine the moderated effects of health insurance (full vs. partial/no coverage*) on the relationships in the path model.



Participants in both groups also described fear of exceeding coverage, gaps in coverage, and uncertainty with the type of coverage offered, i.e. coverage for medical services and therapies specific to participants' needs. One participant in the partial/no insurance group described confusion regarding covered benefits under a private insurance plan:

> "when I signed up for this HSA [Health Savings Account], high deductible health plan, I looked through the book, and I went back and looked, nothing in there said prescriptions were part of it. Had I know that – because I was sick. I got sick in October, 2010. I was sick all through 2011. And had I known that my prescriptions were going to be at full price—I would not have done that. So, I had to wait until March because I had no money once I, you know, they told me what was wrong, I had no money to buy anything, to go to the doctor. So, but it worked out. It all worked out when we finally had the money, that my doctor got the right treatment. But I was in so much trouble in February and March this year. I had no money."

Another participant in the full insurance group described a county, government health insurance plan as insufficient towards meeting her full treatment needs for asthma:

> "I had a government health plan for a minute. They – it's $3 for every prescription. And they didn't pay for Advair. They didn't pay for Singulair. But they give you insurance. Yeah, I mean, I got to see the doctor. But prescription-wise. Yeah, like it's still money. I'm making nothing. It's a Catch-22."

In both focus groups, the frequency of formulary changes with health insurance plans was commonly cited among participants as another fear of having sufficient funds to manage their asthma. One woman in the partial/no insurance group noted formulary changes:

> "You just hope and pray it stay the way, you know, if you got insurance, you just hope and pray it don't change. But don't – the thing, too, with insurance, every time you look up, you'll get your prescription filled, they'll change it to something else."

A woman in the full insurance group also expressed similar sentiments:

> "My insurance does that a lot. Like, several with be on the formulary and then it's not on the formulary anymore, they love the change in formulary."

With Medicaid, uncertainty with coverage was described in the context of administrative turnover. One woman in the full insurance group expressed frustration with maintaining continuous coverage through Medicaid in order to access her therapies:

> “Medicaid and everything is so crazy because you’ll get a new caseworker, and they’ll stop your Medicaid until the new caseworker gets the paperwork. And I’m like, “you can’t stop my medicine. I have to have my medicines.” I’m like, “what are you doing?”

Finally, although individuals with Medicaid described nominal out-of-pocket costs with asthma therapies, several participants in the full insurance group expressed challenges with the time required to reconcile false medical bills. One woman in the group noted:

> “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 have still 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. It’s very

Discussion

This study examined indirect relationships between demographic and clinical characteristics within a high risk population with asthma and perceptions of financial burden. This is the first study to examine these relationships in an adult population with asthma. Half the sample reported perceptions of financial burden, a much higher rate than previous work in pediatric asthma (Patel et al, 2012), and work examining perceptions of asthma-related financial *barriers* measured by access and delaying care (Knoeller et al., 2011). Bivariate analyses showed more individuals with private, non-Medicaid or non-Medicare government, or no health insurance, high out-of-pocket expenses, poor asthma control, and who seek care from a specialist, perceived financial burden compared to individuals who did not perceive burden. These findings reinforce previous work showing economic, demographic, and clinical differences between individuals who report financial-related challenges with asthma care compared to those who do not report these perceptions (Karaca-Mandic et al., 2012; Patel et al., 2012; Knoeller et al., 2011; Nguyen et al., 2011, Scal et al., 2008).

This study went a step further than previous work, and supported hypotheses that demographic and clinical characteristics of individuals with asthma influence perceptions of financial burden through their economic characteristics. Household income, type of health insurance, and out-of-pocket expenses explained relationships between perceptions of burden and being married, having more education, and being employed, while multiple morbidities and total number of medications influenced perceptions of burden via out-of-pocket expenses. No direct relationships were found between household income and perceptions of burden; rather, household income influenced perceptions through health insurance and out-of-pocket expenses.

Marriage, higher educational attainment, and employment were indirectly associated with perceptions of financial burden in this study. The socioeconomic literature suggests that higher educational attainment and employment provide opportunities for socioeconomic mobility (Adler & Newman, 2002). Economic theory posits that risk-pooling and generating economies of scale are benefits of marriage (Becker, 1973). Demographic characteristics typically suggestive of more financial security may manifest differently in influencing perceptions of health-related financial burden. The complex relationships between rising costs, policies, and other sectors of the economy affected by the current economic climate may complicate the provision of affordable health care coverage, and factors that conventionally contribute to social mobility and economic security. Several structural factors may explain these findings and how these relationships may be particularly magnified in a high-risk population.

Married women may not qualify for some safety net health insurance programs (e.g. Medicaid or State-sponsored programs for families with limited resources), due to their marital status or exceeding income requirements. Additionally, some women in this sample may have been limited in their ability to generate economies of scale from marriage. Two-thirds of participants in this sample were heads of their household and reported annual household income of $40,000 and less. Circumstances that have impacted African American communities may also explain the limited ability for women in this sample to generate economies of scale. Data suggests that African American women are more likely to marry mates who are lower in educational and occupational status than themselves, due to high rates of unemployment, underemployment, and incarceration among men in communities that are predominately African American (Jackson & Willams, 2006).

Increasing debt associated with higher education may explain indirect associations between educational attainment and perceptions of financial burden. The qualitative investigations revealed that participants considered the pursuit of further education as important to their future economic security. Although higher education provides more economic opportunities, it comes at a price; women in this sample may have perceived financial burden due to educational debt that may tax their existing resources. In 2012, the average student loan balance for all age groups was $24,301 (Federal Reserve Board of New York, 2012), and the majority of borrowers who are still paying back their loans are in their thirties or older (Federal Reserve Board of New York, 2012). Among women in this sample who were 30 years and older, nearly half reported completing some college, vocational training, or an associate's degree, and one-third reported an educational attainment of college or above.

The impact of the rising cost of healthcare on wages and employee benefits may explain the indirect relationships between employment and perceptions of financial burden. The comprehensiveness of employer-sponsored health insurance has eroded over the past decade (Kaiser Family Foundation, 2010), leaving those with insurance with increased out-of-pocket expenses when they seek care and higher premiums that come out of wages. Fewer workers, particularly those with lower wages, are offered employer-sponsored insurance, and fewer among the workers that are offered such insurance can afford the premiums (Institute of Medicine, 2009). The population in this sample may be particularly vulnerable to changes in wages and health benefits. The majority of African American women work in industries dominated by government, nonprofit employment, health, social services, and education (Jackson & Williams, 2006), which have experienced downsizing and cuts in federal and state spending over recent years.

There may be a couple of reasons why more chronic conditions was associated with fewer out-of-pocket expenses, and therefore fewer perceptions of financial burden in this sample. One reason may be due to classical suppression. Classical suppression occurs when one predictor is uncorrelated with the criterion but receives a nonzero beta weight controlling for another predictor (Kline, 2011). Multimorbidity and out-of-pocket expenses were not correlated in this sample when other factors were not controlled. Individuals with full insurance had more chronic conditions than individuals with partial/no insurance, and thus may have had greater financial protection with their health insurance. Those with full insurance, as defined in this study (a group that typically comprises the low-income and elderly), also have the greatest risk exposures to chronic disease. Another reason for the observed, indirect relationships between more chronic conditions and perceptions of financial burden may be due greater ability to navigate the health care system from experience that may be evident among those with more disease burden. These individuals may already be seeking out resources to assist with their out-of-costs.

Strong relationships were observed between household income and health insurance that may also be indicative of this sample. Such associations may not always be as strong given that individuals with private or no insurance or Medicare (full insurance) comprise a range of individuals from the working and non-working poor, middle income, to affluent. This sample was predominately low-income.

Greater number of medicines was associated with perceptions of financial burden via out-of-pocket expenses. The descriptive findings also confirmed that asthma medicines were perceived as financially burdensome by the greatest number of individuals in this sample. This finding suggests that total number of medications may be the clinical factor most predictive of perceptions of financial burden given the associated cumulative out-of-pocket expenses. This particularly impacts individuals with asthma, as most asthma medications are still patented under their brand name.

The effects of household income on out-of-pocket expenses and perceptions of financial burden differed between the full insurance and partial/no insurance groups. The findings suggest that household income matters for how much individuals pay out of pocket if they have full insurance, but this is not the case for individuals with partial/no insurance coverage. This makes sense given that Medicaid programs set cost-sharing requirements for beneficiaries based on family income; however, cost-sharing charges cannot exceed 5% of their income (U.S. Department of Health and Human Services, 2008). Similar policies are evident for other state sponsored health insurance for people with low income. No such policies are evident for the private insurance market or those without health insurance coverage, therefore this sizable group has no protection from policy concerning how much of their income or assets may go to financing their health care out-of-pocket.

For both the full insurance and partial/no insurance group, out-of-pocket expenses were significantly associated with perceptions of financial burden. These findings reinforce the fact that individuals with all types of health insurance plans perceive financial burden due to out-of-pocket expenses. Although the common perception is that full insurance plans provide comprehensive coverage, some individuals still perceive out-of-pocket expenses as burdensome; especially those who have more income.

The findings from this study also suggest that perception of health-related financial burden is conceptually complex and may not necessarily imply low or inadequate economic resources. Burden may also imply acquisition and retention of economic resources. Findings from the focus group revealed that false bills and challenges with maintaining continuous insurance coverage was quite common for the full insurance group, and contribute to their perceptions of burden. The fact that women from both focus groups described living from paycheck to paycheck and the ambiguity of their economic situation given the changing economic climate, provide support that perceptions of burden may also encapsulate feelings of uncertainty.

Half of this sample did not report perceptions of financial burden despite what their financial resource options objectively suggested; two-thirds of this group had partial/no insurance coverage and more of this group was in the lowest income category compared to those who perceived burden (46% vs. 39%). Social desirability may certainly be one reason why perceptions of financial burden may be underreported. Finances are a sensitive topic for many individuals, and participants may not have been comfortable answering such questions or openly discussing their perceptions about their financial situation in a focus group.

On the other hand, if in fact these are true appraisals of participants' situations, there may be other factors present that buffer the effects of individuals' economic circumstances on perceptions of financial burden. The qualitative findings described participants' coping strategies with respect to financial burden such as stockpiling medicines, praying, accepting situations as they are, or relying on supportive social networks. Social networks have been shown to be instrumental in buffering the effects of stress in the population that represents this study population. The extensive support systems within African American communities that often go beyond the immediate family are described as the first line of defense when dealing with stress (Constantine, Wilton, & Caldwell, 2003; Bagley & Carroll, 1998). It may also be plausible that participants are already receiving support from their health care provider in mitigating their perceptions of financial burden. This will be explored further in the next chapter. Although coping resources were identified, it is not clear whether these are adaptive or maladaptive coping strategies for participants. Assessing these relationships was beyond the scope of this study, however, coping strategies may differentially influence health outcomes. Further examination of the effects of patients' coping strategies with financial burden on their health is an opportunity for future research.

There are several limitations in this study that should be noted in considering the implications of these findings. The concurrent mixed methods approach revealed limitations in terms of the ability to use qualitative data to clarify the quantitative approaches. The opportunity to use qualitative data to inform the measures and specify more complex pathways in the analytic models would have provided a more adequate assessment of the relationships of interest, and perhaps fit the model closer to the data.

SEM procedures including path analysis, requires measures to have strong psychometric properties to ensure stable statistical estimation (Kline, 2011). Data were self-reported, therefore some responses may not reflect actual perceptions or the economic circumstances of participants in this study. For example, self-report measures of questions related to socioeconomic status can be more positive than is the case (Stone, 1999). Existing tools to measure out-of-pocket expenses associated with health care and perceptions of financial burden may be conceptually inadequate. Psychometric properties of existing measures of perceptions of financial burden are unknown and may not capture the specific focus of burden as it relates to disease management. Additionally, the mode of data collection used to assess perceptions of financial burden may bias responses, given that the discussion of finances is often sensitive. Although theoretically meaningful constructs can be developed by using latent variables (which improve the measurement quality of data and adjust for random measurement error), latent factors that would comprise perceptions of health-related financial burden have not been examined and provide opportunity for further exploration. The measure concerning household composition may have also not captured non-family members or other members of a participant's social network dependent on the household income. The measure used to assess out-of-pocket expenses only assessed the cost associated with medicines, and may not have captured all of the out-of-pock expenses that participants may incur with their asthma-related disease management. Therefore, participants' out-of-pocket expenses in this study may be underreported. Few measurement tools aside from self-report recall exist to ascertain out-of-pocket expenses. Diary approaches may usefully mitigate the limitations associated with recall, and enhance the ability to capture a comprehensive picture of out-of-pocket expenses associated with asthma. These include lost work time, and expenses related to transportation, health care visits, and environmental modifications.

Given changes in federal and state health insurance programs characteristic of an unpredictable economy and the recent passage of the Patient Protection and Affordable Care Act, the classification of types of health insurance in broader categories of “full” and “partial/no” insurance may not reflect these evolving trends. Some private insurance plans are also more comprehensive than government sponsored insurance or perceived as such, however data on the comprehensiveness of private insurance plans were not available in the data sources. Additionally, the asthma-related formularies for the types of health insurance surveyed may be different than the amount of broader coverage plans typically provide.

Although the qualitative findings in this study revealed that participants utilize coping resources to assist with cost-related challenges, the lack of quantitative data available to quantify the use of specific coping resources precluded estimation of coping as a possible mediator in the relationship between clinical and demographic characteristics and perceptions of financial burden. Coping may be an omitted variable that contributed to low correspondence between the model and data.

The ability to note subtle distinctions in variables collapsed via Likert response scales or response distribution may have been lost. To address this, collapsed variables were checked to see if they achieved similar results when collapsed in a different way around cut-points. Results demonstrated similar results in the same direction.

The data were cross-sectional; therefore, the true direction of association between some variables may not be easily discerned. Longitudinal data would provide more opportunities to examine reciprocal or non-recursive relationships between perceptions of financial burden and economic, demographic, and clinical characteristics.

Since this study utilized secondary data for the item-specific survey and in-depth interview data, limitations were that items may have been measured differently than anticipated, or limited to what already exists or may be incomplete. With the qualitative data collection obtained through focus groups, social desirability and the group format may have precluded individuals from sharing their true experiences with financial burden.

Finally, the study sample comprised African American women receiving care in Southeast Michigan. As a result, findings may not be generalizable to all women or all adults with asthma or those receiving care in other regions. Because inclusion criteria for the study required participants to receive care for their asthma, the number of individuals who report not having a health care provider may be greater than reported here.

Despite these limitations, this study has strengths. Perception of financial burden is prevalent. This study identified influential economic mediators that are important for understanding how patient characteristics manifest relative to perceptions of financial burden. Factors typically suggestive of economic security such as marriage, employment, education indirectly led to greater perceptions of financial burden in a high-risk population. Perceptions of financial burden are evident despite having economic resources and among individuals with all types of health insurance and those without insurance. For individuals with full insurance (for whom limited resources are a common reality for the majority of this group), greater income increases expectations to pay out-of-pocket for their asthma care. For those with private or no insurance, income has no bearing on how much individuals will pay out-of-pocket for health care. Lastly, perceptions of health-related financial burden may go beyond just having access and resources and encapsulate the quality and utility of resources related to access to care.

Implications

Key findings from this study have a number of implications for research and clinical practice.

Research

The majority of research to-date on patient financial burden with health care has quantified the level of burden across the population based on out-of-pocket expenses in relation to income or health insurance coverage. When measured as such, several studies have shown that financial burden shows strong associations with poor health outcomes. Since this study found that perceptions of financial burden is evident despite having resources, and other work has shown that perceptions are also associated with poor outcomes (Patel, Brown, & Clark, 2012), better measures to quantify and document the level of financial burden in the population (both actual and perceived) may be needed in order to better inform public health and policy efforts around mitigating burden for a potentially large segment of the population. Measures may capture the continuity and comprehensiveness of health insurance, and include individuals' subjective appraisal of their out-of-pocket health care costs.

Mixed methods approaches are imperative to understanding complex relationships between individuals' context and their perceptions of financial burden. Future studies may consider sequential mixed methods study designs whereby qualitative data inform conceptual linkages and model specification, the development of quantitative measures, data collection and analysis before hypothesis testing. A sequential design may also help to elicit and inform the inclusion of community and structural level factors in an analytic model, which may also influence perceptions of financial burden. Future research may also continue to utilize multiple formats of qualitative data collection, given limitations that social desirability poses in group formats.

Qualitative findings suggested that coping strategies related to financial burden may be both cognitive and behavioral. Measures that make a distinction between coping strategies are recommended for future work. Coping strategies may also prove adaptive or maladaptive; studies that make clear the effects of such strategies may aid the development of interventions. Adapting scales that assess John Henryism or high personality hardiness is recommended for future work. 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 among communities that have been historically marginalized (James, 1994). 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 (Huang, 1995), has been shown to buffer the effects of stress on illness among women compared to low hardiness women (Williams & Lawler, 2008).

Exploring relationships between clinical, demographic, and economic characteristics and perceptions of financial burden in heterogeneous samples where findings can be more broadly generalized is recommended. Additionally, chronic diseases may vary widely in terms of aspects of disease management that patients’ perceive as financially burdensome. Future studies may explore the relationships undertaken in this study in other chronic disease populations to ascertain similarities and differences between chronic conditions and perceptions of financial burden.

Recent reforms from the 2010 Patient Protection and Affordable Care Act will provide opportunities to explore patient perceptions' with maintaining affordable coverage. Future research may continue to examine individuals' perception of financial burden with implementation of these new policies.

Future research may consider exploring perceptions of finical burden across time using longitudinal data. Such research may provide insights to what factors contribute to the magnitude of perceptions over time.

Future research may also consider other analytic techniques that fall within the SEM family to examine pathways to perceptions of burden. One example is the use of latent factors, to simplify models, or estimate the unique contribution of constructs that may pose measurement limitations such as perception of financial burden. Alternatively, future research may also continue to refine measures for assessing perceptions of health-related financial burden and patients' out-of-pocket expenses. A next step for research is also to re-specify the model, and consider alternative models and interactive relationships between variables.

Clinical practice

The recent passage of the Patient Protection and Affordable Care Act (PPACA) will provide millions of uninsured Americans with health insurance coverage. Cost, quality, and access challenges will still persist with the PPACA reforms. Actuarial principles that underlie health insurance, based on the pooling of risk to balance and offset costs assure that an increasing population with chronic disease will continue to make out-of-pocket expenses a common reality for those utilizing health care services. Patients' out-of-pocket expenses will be evident regardless of the provision of health insurance, the kind of health insurance, and the availability of federal subsidies through recent reforms. Since clinicians provide therapeutic recommendations and play an instrumental role in facilitating chronic disease management, especially among individuals with asthma, the findings presented here provide opportunities for communication between provider and patient.

Clinical implications of this work include the ability of health care providers to better understand how financial burden may manifest for their patients. Individuals who have resources to access health care may be at just as high of a risk for poor outcomes as those without access to care, irrespective of the type of health insurance coverage they have. Access to care is a necessary first step, but given the rising costs of health care, it may be just a first step for many. Clinicians may be more aware of the out-of-pocket expenses their patients are incurring, especially as a result of the volume of medications prescribed and whether their prescribed medications are offered on the formulary of their health insurance. They may also be aware of challenges with continuous coverage or false bills that patients face, regardless of the type of health insurance coverage they have.

Inquiring about patients' ability to pay and access the resources they need to manage their health may be difficult for clinicians given that these skills are not typically taught in medical curricula (Cooke, 2010). Although the findings from this study suggest that perception of financial burden is prevalent among patients, identifying patients that prefer to have a discussion with their clinician about cost and what this conversation should entail is not clear cut. The next chapter will describe how participants' preferences for cost-of-care related communication with their health-care provider manifest, and their experiences utilizing community resources to address their burden.

Conclusion

More than half of women with asthma reported perceptions of financial burden. Demographic characteristics suggesting more financial security were not necessarily aligned with lower perceptions of financial burden. Burden may be present despite having economic resources and health insurance, and such individuals may also be at risk for poor outcomes. Awareness of factors beyond access alone that may contribute to perceptions of financial burden may be needed by clinicians to assist patients who need help understanding options to reduce such burden.

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Appendix 4.A: Self-care among African-American women with asthma and other health conditions: Interview protocol.

[*First, complete informed consent process*].
I have a number of questions for you about how you manage your health on an everyday basis. Let me tell you a little about what this interview is going to be like. You've already done surveys for our project where someone asks you a question, gives you a choice of answers, and then you pick one. Today's interview won't be like that at all. Instead, I'd like the interview to be more like a conversation. I'm hoping you'll feel free to share lots of details and stories about your experiences with managing your health, because what we learn from you will help us improve the services we offer to people like you who are managing more than one health condition. I'm interested in your experiences, thoughts and opinions—there are no right or wrong answers.

Like we talked about when we were going through the consent form, I just wanted to remind you once again that nothing you say will ever be identified with you personally; we're just going to combine all the comments of all the women we're interviewing and look at them as a group. As we go through the interview, if you have any questions about why I'm asking something, please feel free to ask. Or if there's anything you don't want to talk about, just say so. And please also tell me if you don't understand what I'm asking. Any questions before we begin?

PART 1: GENERAL HEALTH AND SELF-MANAGEMENT INFORMATION

1. To start with, please tell me about your health right now.

1a: [*look at completed survey; verify diagnoses*]. I see that you've marked [X], [Y], and [Z]. (if haven't already talked about one of these in 1. above]—How does [X] affect you? *[probes: daily living, holding a job, taking care of others, having fun, etc.]*

2. Please describe what you do on a typical day to take care of your asthma and other health issues. *Note: "walk" participant through her day with "anchor points"—getting up, getting ready, breakfast, work or other activities, lunch, dinner, evening, bedtime*.

2a. *After gone through day:* It sounds like you spent the most time taking care of [X]. Would you say this is usually how it is? [*probe for medication taking at each point if not mentioned*]

3. When you think about having to manage multiple health problems—[X], [Y], and [Z] –all at the same time—what is the biggest difficulty you face?

PART 2: PRIORITIZATION OF ILLNESSES AND SELF-MANAGEMENT TASKS

Now I have a few questions about how you make decisions about caring for your health.

4. Which of your health problems seems most important to you right now? Why do you feel that way?

PROBE: Do you consider any of your health problems to be your 'main' health problem? Why?

5. Which of your health problems do you worry about the most? Which do you worry about the least?

6. Are there times when taking care of ___*other health condition*___ makes it difficult to take care of your asthma? Please give me an example. What about the reverse—does taking care of your asthma make it hard to take care of your __*other health condition*_? [*example if needed: for example, you have to do a lot of housecleaning for your asthma but your arthritis makes this difficult*]

7. Can you tell me about any of the things you do to take care of yourself that you think help more than one of your health conditions? [*GIVE EXAMPLE: stress reduction benefitting both asthma and heart disease*]

8. Let's shift gears a little now to medications. Please tell me about the medications you take. 8a. What is the cost of these medications? 8b. Can you tell me about any trouble you have juggling multiple medications?

9. There are a lot of different reasons why people might miss doses of the medication that the doctor tells them they should be taking. Can you tell me about the times that this has happened to you? For which medication/condition are doses most often missed?

PART 3: SYMPTOM EXPERIENCE AND MANAGEMENT

Now I'm going to move on to talking about your experience with symptoms.

10. Are there any symptoms you experience daily, or regularly? By symptoms I mean things like pain, or anything else you feel that bothers you. What are they? [*probe: Any others? Probe specifically for fatigue if not mentioned*]

11. [*If mention more than one*]—which of these symptoms would you say most gets in the way of doing what you need to do each day?

ASK ABOUT SIDE EFFECTS

12. Why do you think you have ___________? [*ask only if attribution not mentioned above*]
How do you control or cope with__________? [repeat for each symptom]

13. Please tell me about any uncertainty you have in knowing which of your health problems is causing your symptoms. [*If the interviewee acknowledges any uncertainty, probe*: how does

not being sure about where the symptom is coming from affect how you use your medicines? How do you decide which doctor to call?]

PART 4: SOCIAL CONTEXT OF ILLNESS MANAGEMENT

Now let's talk about some of the other things going on in your life that might affect how you take care of your health.

14. What major responsibilities do you have as part of daily life?

    PROBE: Sounds like you're a [active person, busy grandma, etc.] How does your family/work life make it hard for you to do what you need to do to take better care of yourself?

15. [*if not mentioned above*] Who are the people that you help, or help take care of, besides yourself?

    PROBE: What do you do for _____________? (repeat for each person mentioned)

    PROBE: Tell me about how helping or taking care of these people affects how you take care of yourself.

    PROBE: Can you tell me about the health of the people you take care of? [probe about any medication sharing if any shared conditions]

16. Would you say that there are situations in your life that make it more difficult for you to take care of your health? For example, sometimes women tell us that having so much on their plates or financial stress makes it difficult. Are there things going on in your life that get in the way of taking care of your health?

17. Which of your health problems do you spend the most money on? How about the least? [probe if they don't mention: for which do you spend the most money on medications?]

18. To what extent do you think the other people in your life understand what you need to do to take care of your asthma and other health issues?

19. Can you please tell me about the help you get from your family or your friends in managing your health conditions? [*PROBES: Which of your health problems do you need the most help with? How about the least help? In what ways do you need more help?]*

20. Is there anything that people do that actually makes it harder for you to manage your health conditions?

PART 5: POSITIVE ILLNESS MANAGEMENT EXPERIENCES

So far, I've asked you to talk quite a bit about challenges and problems. Now I'd like to hear more about your accomplishments and successes.

21. This next question might require some thought, so feel free to take some time before you answer. What are some ways that you have been successful in managing your health? PAUSE What comes to mind? *PROBE:* Why do you think you've been so successful at this?

PART 6: HEALTH CARE AND SERVICES

For the next set of questions, we'd like to hear about your experiences with health care providers.

22. I'd like to ask you about the various doctors or other health care providers you see for your health problems.

  [*For each condition named at beginning of interview, ask:]*

  22a. Which doctor do you see for your [condition]? [*probe: primary care vs. specialist*]

  22b. Who do you call first if you have a problem with your [condition]?

  22c. If you have just a question about your [condition], but not anything urgent, who do you try to get the answer from? [*probes: primary care provider, specialty care provider (MD or nurse), pharmacist, friend, internet, support group*]

23. When you are seeing one of your doctors, how do you decide which illnesses to discuss? [*probe if they don't mention PCP: which illnesses do you discuss with your primary care doctor?]*

24. Can you tell me about any situations you've faced where the recommendations of one doctor for one of your health problems has affected another health problem? [*probe: any trouble with medications in this way?]* How about conflicting advice from doctors?

25. Please tell me about any difficulty you've faced regarding lack of communication among the different doctors that you see. When has communication been successful?

26. Is there anything you wish doctors or other health care providers would understand about what it is like to manage more than one health condition?

27. Can you think of any kind of education or support that you are not currently getting from your health care providers that would be helpful to you?

PART 7: CONCLUSION

28. [*if they have more than 2 chronic conditions only*] Thinking about everything we've talked about today, which two of the (X) conditions that you've told me about are the most troublesome to manage together? What is it about this combination that is especially difficult?

That covers all of my questions. Can you think of anything else I should have asked to help us better understand your experience with taking care of more than one health condition?

Thank you so much for your time today.

Appendix 4.B: Focus Group Discussion Guide- Perceptions of financial burden and patient-provider communication among women with asthma.

Before we begin, you have a consent form and a brief questionnaire that we would like for you to take five minutes to fill out. They are located in the folder in front of you. {*Wait until everyone is done filling out the consent form and questionnaire*}

Thank you for coming today. My name is [INSERT MODERATOR'S NAME] and I will help facilitate our discussion today. I'd like to welcome you to our group discussion about some of your experiences with your health insurance plan and managing asthma. We'll also be talking about experiences with talking to your health care provider about what your insurance covers for your asthma. This is an opportunity for you to share your experiences living with and managing asthma and interactions with your doctor.

I am a graduate student at the University of Michigan School of Public Health and I became interested in patients' cost with their medical care and communication with health care providers after working in hospitals as a research assistant for a few years. I was working with people who had sleep apnea, and issues around health insurance and how expensive the treatments were seemed to be a common conversation that I would have with patients of the doctor I worked with. I would also constantly see articles in the newspaper about how expensive health care is getting and different and often times difficult situations that patients are going through as a result. This made me want to study communication and patients experience with their health care costs because I think if more was known about what people actually go through to manage their health and that of their family, or understand things working well, we can better assist people with what they really need. That is what I hope to do, and I hope that having all of you share your insights and experiences with me will allow me to better serve you and other people you know in order to make getting health care easier. I appreciate that you're taking the time to be here today and share what you know with me.

[INSERT CO-FACILITATOR'S NAME] is here to help me by taking notes; she may point someone out if I don't see you trying to get my attention and may ask some questions. Our job is to listen, make sure that everyone has a chance to speak and to follow-up on points that are made. [INSERT CO-FACILITATOR'S NAME] will go ahead and tell you a little bit about herself. [INSERT NOTE-TAKER'S NAME] will also be taking some notes during the discussion. [INSERT NOTE-TAKER'S NAME] will go ahead and tell you a little bit about himself.

This discussion will be much like sitting down and talking with a group of your friends. There are no right or wrong answers. I am interested in hearing your opinions and ideas. With this in mind, you are not expected to agree with anyone else in the room if that's not how you feel. However, it's important that we do hear what you have to say.

There is a name tent in front of you that we would like for you to write whatever name you'd like to be addressed by during this conversation. You are free to use whatever name you want and it does not have to be your real name. If you could say your name before you speak during this discussion, that would be great.

Information discussed in the session should not be shared with anyone. Please remember we will tape record the session in order to accurately record your ideas. Files will be kept in locked rooms at the University of Michigan School of Public Health. There will be no names or other participant identification used in any project reports.

As participants of this group you have agreed to protect each other's privacy and will not share any of the information discussed today. During the discussion it is important to speak one at a time so that we can be sure to hear everyone's comments. Before we begin, we'd like for everyone to turn off their cell phones or put them to silent. Do you have any questions before we begin?

So that we have plenty of time to talk about your experiences, let's start by quickly having you introduce yourself. Please say your name and why you decided to participate. Please also tell us what is one thing or person you would want to have with you if you were stranded on a desert island. I'll go ahead and begin. My name is Minal Patel, and I'm here today to learn more about your experiences with managing asthma. If I were stranded on a desert island the one thing I would bring is…

It is nice to meet all of you and I'm glad we can get to know a little bit more about each other. I'd like to start off by asking you some questions about your asthma management.

1) How long have you been living with asthma?

2) 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?]

3) 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?

4) 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. As a student, sometimes when I go to the doctor when I'm sick, I get very frustrated with my doctor when he or she tells me to do something that costs me as much as I need to spend on my groceries for the month and my health insurance won't cover it. 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.]

5) Copays are changing and sometimes we don't even know that this is happening until we're 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?
    a. 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]
6) 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?
    a. Many people have to move around their financial responsibilities to make everything work for them and their family. I know that when I had to have some emergency dental work done last year, I had to be very careful about my spending and managing my bills during that particular month. What kinds of things do you have to switch around? How much "clever management" do you do to make this all work?
    b. What are some things that you are or feel responsible for at this point in your life?
    c. What are some things that are important to you or a necessity alongside managing your health?
7) We just finished talking about some of your experiences with managing asthma. Now I want to talk about your experiences with talking to your doctor. I know when I go to the doctor, I have about 10 minutes and I don't get through everything I want to talk about so I imagine that some of you may have this experience as well. Can you tell me a little bit about what it's like when you talk to you doctor?
8) A few moments ago, we were talking about how your financial responsibilities impact your asthma, can you think of a particular time that you wanted to talk with your doctor about this? What was the conversation like? Can you tell me a little bit about what you said? Or if you were not able to talk to them why?
    a. Are there any reasons besides time that kept you from discussing the financial aspects of your asthma management with your doctor?
    b. What would make it more comfortable for you to talk to you doctor about cost?
9) Do you think it's important to have these types of conversations with your doctor? Why or why isn't it important to you and your situation?

10) Is there anyone else in your doctor's office or outside of the doctor's office that is helpful to you in understanding your insurance policy, or assisting you with getting everything you need to manage your asthma?
    a. What do they do that is helpful?
    b. If there isn't anybody, what are some things you would like the doctor to do or other people in the office in order to help you?
11) What are your experiences with using resources in the community to assist you with getting everything you need in order to manage your asthma (e.g. pharmaceutical assistance programs)?
    a. Have you found these services helpful? Why or why not?
    b. If you have not used them, why not? How can your doctor or other staff in the office make it easier for you to learn about or access these programs?
12) Is there anything else you would like to share with me today?

Thank you again for sharing all of your experiences with me. It has really been a valuable experience for me and I hope for all of you as well. It was a pleasure getting to know all of you. As a token of appreciation, all of you will get a $50 Visa gift card. We will need you to sign a form indicating that you received the gift card from us, so if you could take a moment to fill that out before you go, that would be great.

CHAPTER 5

WHO PREFERS TO DISCUSS THE COST OF THEIR CARE WITH THEIR HEALTH CARE PROVIDER AND WHY AMONG WOMEN WITH ASTHMA

Abstract

People with asthma perceive financial burden with managing their conditions. Communication may be one way to address patients' perceptions; however, both clinicians and patients report barriers to discussing the cost of care (cost of care-related communication). The purpose of this study was to 1) identify economic factors that may mediate a preference for cost of care-related communication, and 2) describe patient experiences accessing resources to assist with cost-related challenges. Data were collected through standardized telephone interviews from a study cohort of 343 African American women seeking services for asthma in the Southeast Michigan. Additional qualitative data were collected through sub-samples via two focus groups (n=14) and in-depth interviews (n=25) to provide supporting information. Coded transcripts were analyzed for themes. The relationships between preferences for cost of care-related communication and clinical and demographic factors were examined through hypothesized mediators (household income, health insurance, out-of-pocket expenses, perception of financial burden). Quantitative data were analyzed using path analysis. The mean age of participants was 42.8 years (SD=14.82). Seventy-three percent (n=251) of participants in this sample reported preferences to discuss the cost of their care with their health care provider. Themes regarding experiences accessing community assistant programs revealed that some

people face barriers in accessing them, and programs often require verification from a health care provider. Household income, type of health insurance, out-of-pocket expenses, and perceptions of financial burden mediated the pathway between preferences for communication and 1) being married ($\beta= 0.028$, SE=0.012, $p<0.05$), 2) having some college ($\beta= 0.023$, SE=0.011, $p<0.05$) and a college education or more ($\beta= 0.041$, SE=0.017, $p<0.01$), and 3) full time employment ($\beta= 0.036$, SE=0.015, $p<0.01$). The majority of women with asthma report a preference to discuss cost with their clinician. Individuals with high out-of-pocket expenses and who perceive financial burden are more likely to report a preference, unrelated to the complexity or control of their asthma. These preferences are evident despite factors that may suggest an individuals' ability to access or bear the costs associated with their care. Given the high percentage of women desiring cost-of-care discussion, clinicians may be sensitive to their preferences and attending to needs that may impact their disease management.

Introduction

Asthma is a prevalent chronic condition whose adverse health outcomes and associated costs are quite high (Akinbami, Moorman, & Liu, 2011). Chronic diseases like asthma require lifetime management with a therapeutic regimen and routine interface with the health care system in order to adjust medications and the treatment plan, monitor exacerbations, and guide self-management effort. These requirements can be perceived as financially burdensome given an economic climate in which rising health care costs are being shifted more frequently to patients, and health insurance plans do not provide full coverage for the broad spectrum of services a chronic condition requires. One-third of adults in the general population who have asthma report financial barriers associated with managing their condition (Knoeller, Mazurek, & Moorman, 2011). Patients' perception of financial burden with managing their asthma presents an opportunity for health care providers to support their patients with their disease management and be attentive to related concerns. Unfortunately, the discussion of the cost of care (cost of care-related communication) occurs infrequently between clinician and patient (Alexander, Casalino, & Meltzer, 2003). Cost of care-related communication is dialogue in the clinical encounter concerning the direct, out-of-pocket cost of therapeutic recommendations (e.g. medications, devices, environmental modifications, etc.) for illness management incurred by a patient from their health care. Common barriers to such communication reported by clinicians include discomfort and perceptions that they can offer no solutions to their patients (Alexander et al., 2003).

Six studies have found that both patients and health care providers report a preference to discuss the cost of care during clinical visits (Tseng et al., 2010; Donohue, Huskamp, Wilson, & Weissman, 2009; Tseng et al., 2007; Beran, Laouri, Suttorp, & Brook, 2007; Alexander, Casalino, Tseng, McFadden, & Meltzer, 2004; Alexander et al., 2003). These findings suggest that despite perceived barriers, clinicians recognize that their patients may have financial concerns with their therapeutic recommendations. Findings show that more than 50% of patients report a desire to talk with their physician about their out-of-pocket medical expenses (Tseng et al., 2010; Donohue et al., 2009; Tseng et al., 2007; Alexander et al., 2003), and patient characteristics that directly predict this preference are burden of out-of-pocket expenses, difficulty paying for medications, lower income, and poor health (Tseng et al., 2010; Tseng et al., 2007; Alexander et al., 2004). Other work has shown that more than two thirds of patients who report no difficulty paying for medications still want their health care providers to ask about affordability, consider cost, and discuss lower cost tradeoffs of therapies and their efficacy (Tseng et al., 2010; Tseng et al., 2007). Alternatively, half of patients believe it is inappropriate to discuss costs with their physician (Benedetti et al., 2008). These findings from the existing literature suggest that identifying patients who would like to discuss cost with their provider may be difficult for clinicians and may potentially impede their self-efficacy to initiate sensitive discussions around affordability with their patients. Furthermore, how preferences for such communication manifest for patients is not clear, thus limiting a full understanding of how clinical and economic characteristics such as poor health and low income, may lead to a communication preference about cost.

Patients may already be aware of and utilize strategies to manage their out-of-pocket expenses related to their chronic disease management. Rising costs of prescription drugs over the past decade has led to a greater availability of programs to assist patients with accessing affordable therapies for chronic diseases (Czechowski, Tjia, & Triller, 2010). Such programs are often sponsored by pharmaceutical and medical device manufactures. Data suggest that the use of such programs has risen over time (Gatwood et al., 2011), and patients are utilizing a variety of methods to reduce their prescription costs (Kaiser Family Foundation, 2010). However, disparities exist in the utilization of resources to assist with the cost of therapies (Gatwood et al., 2011). No studies have examined what patients may already be doing to manage their drug costs or the potential barriers to accessing assistance programs among individuals with asthma.

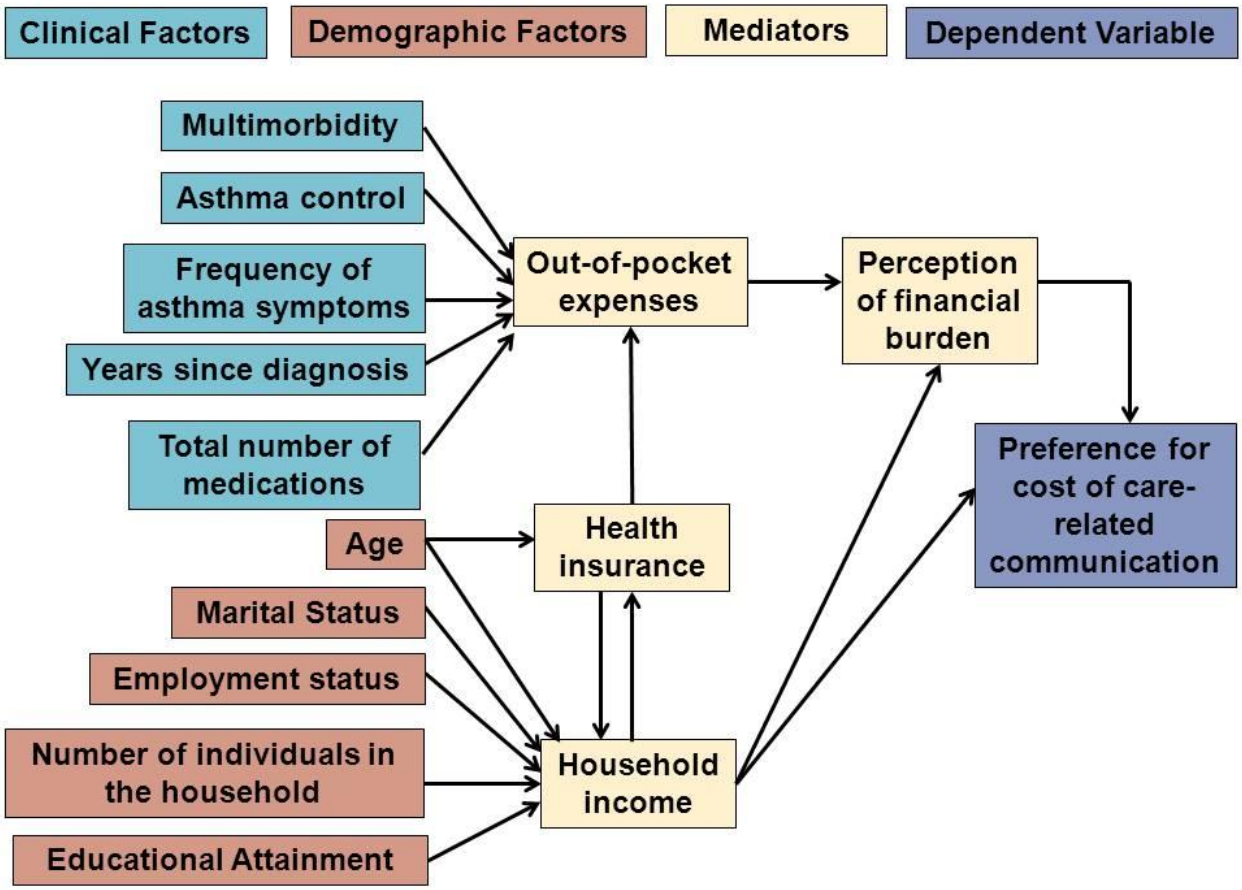
African American women comprise a vulnerable population for which preferences for cost of care-related communication and experiences accessing resources to address financial-related challenges, merit further exploration; they are disproportionately affected by asthma, face the greatest challenges with self-management, have disproportionately high urgent care use for asthma, and experience worse asthma health outcomes compared to other subgroups (Centers for Disease Control and Prevention, 2011). They have increased asthma-related risk exposures and may be vulnerable to perceiving financial burden with asthma management due to persistent racial and gender disparities in economic opportunities (Jackson & Williams, 2006). African American women may be especially vulnerable to communication challenges in the clinical encounter. Physicians have been shown to be less patient-centered in their communication approach with African American patients compared to non-Hispanic white patients (Cooper & Roter, 2003; Cooper-Patrick et al., 1999). As a result, a preference for cost of care-related communication and the need for supportive resources to address perceptions of financial burden may be particularly high for this population.

Preferences for cost of care-related communication have not been examined among individuals with asthma and vulnerable populations. No studies have explored the pathways through which patients' demographic and a broader range of clinical characteristics influence a preference for cost of care-related communication. Some evidence suggests that clinicians change their practice patterns based on their perceptions of patients' ability to pay given the type of health insurance they have (Patel, Coffman, Tseng, Clark, & Cabana, 2009; Reichert, Simon, & Halm, 2000). For example, being less mindful of costs for privately insured patients even though out-of-pocket expenses are often much higher for privately insured patients compared to individuals on government sponsored plans (Patel et al., 2009).

Further investigation of how preferences for communication manifests from health insurance merits further exploration. A better understanding of how patient factors lead to a preference for cost of care-related communication may help clinicians better tailor their communication strategies with their patients and better anticipate when it may be appropriate for them to initiate such a discussion. An in-depth examination of patient experiences with community health resources to manage the costs of asthma therapies may also help clinicians better understand patient barriers and inform their strategies to assist their patients.

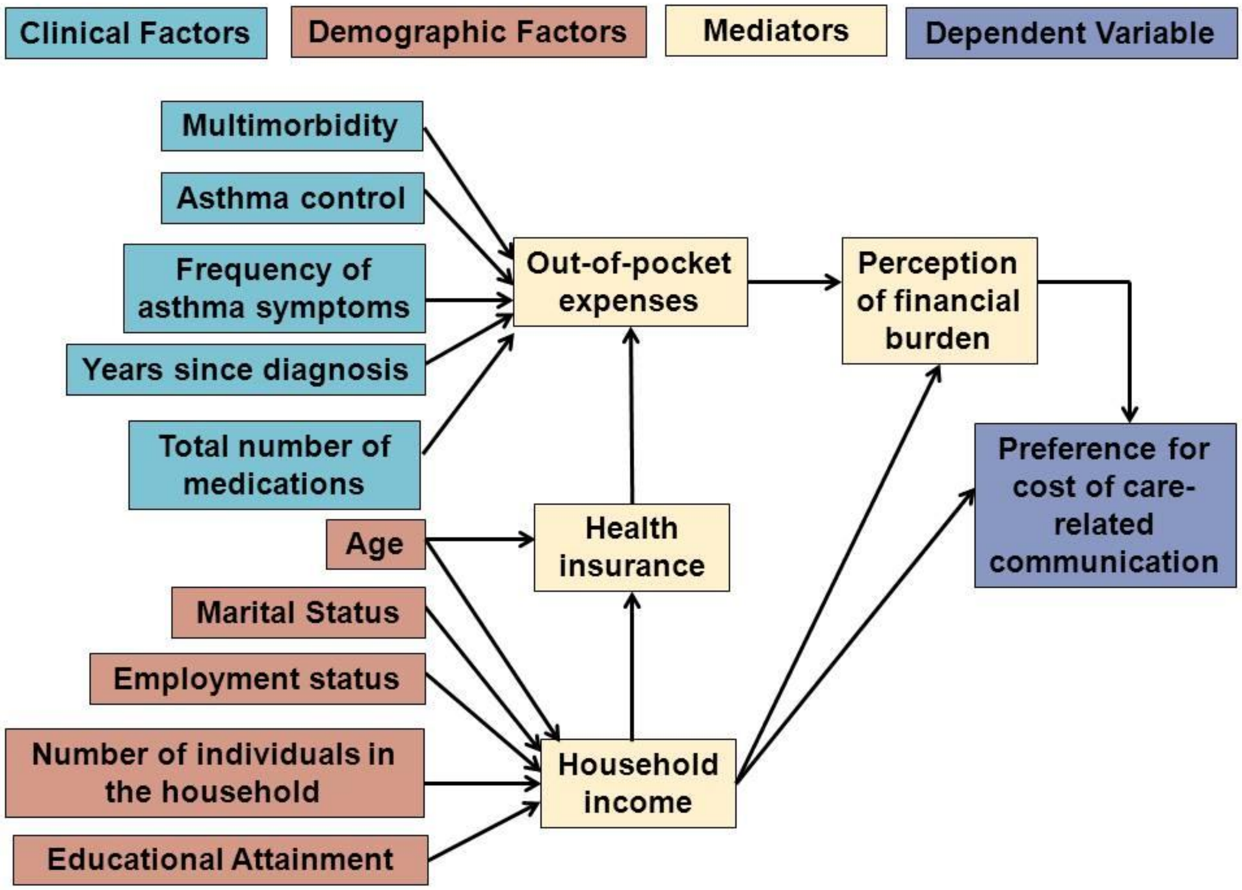
The purpose of this study was to examine 1) the indirect relationships between demographic and clinical characteristics of women with asthma and preferences for cost of care-related communication with their health care provider, and 2) their experiences accessing resources to assist with cost-related challenges. Economic factors (health insurance, out-of-pocket expenses, household income) and patients' perception of financial burden may mediate relationships between preferences for cost of care-related communication and their demographic factors (educational attainment, number of individuals in the household, age, marital and employment status) and clinical factors (multimorbidity, asthma control, frequency of asthma symptoms, years since initial asthma diagnosis, total number of medications) (see Figure 5.1). In Figure 5.1, household income and health insurance demonstrate a reciprocal relationship, as theoretical support suggests that health insurance and income affect each other (Baicker & Chandra, 2008).

Figure 5.1: Conceptual model depicting influences of preferences for cost of care-related communication.



Preliminary analysis showed that the effect of health insurance on income did not demonstrate a significant relationship; therefore this relationship was dropped in order to simplify the model. Only the effect of income on health insurance was estimated. Figure 5.2 shows the analytical model empirically tested in this study.

Figure 5.2: Analytic path model depicting influences of preferences for cost of care-related communication.



This study explored three hypotheses depicted in Figure 5.2:

Hypothesis 1: The relationship between demographic factors and preference for cost of care-related communication will be mediated through household income, health insurance, out-of-pocket expenses, and perceptions of financial burden.

Hypothesis 2: The relationship between clinical factors and preference for cost of care-related communication will be mediated through out-of-pocket expenses and perceptions of financial burden.

Hypothesis 3: Health insurance will have a moderating effect on some of the relationships in hypotheses 1 and 2.

Methods utilized in this study are described next, followed by results, and a discussion of the findings.

Methods

The data source, sample for this study, data collection and measures, and qualitative methods are described in full in the previous chapter. New variables and methods introduced in this study are described in full here. Perception of financial burden described in the previous chapter is now a mediator in this study.

Measures

Preferences for cost of care-related communication

In this study, preference for cost of care-related communication was operationalized as how important a participant considers the need to discuss cost with their health care provider. To measure preference for cost of care-related communication, participants were asked the following question: “how important it is to you to talk with your doctor about your out-of-pocket costs?” Response choices were measured on an ordinal scale (very important, important, somewhat important, not at all important). Assessment of preference of cost of care-related communication has shown consistent findings across studies with similar measures (Beard et al., 2010; Benedetti et al., 2008). The final measure of preference for cost of care-related communication was used as an ordinal variable in this study.

Data analysis

Intraclass correlation coefficients (ICC) were calculated in SAS 9.3 in order to assess for potential clustering of responses on preferences for cost of care-related communication by individuals seen by the same health care provider (ICC=0.36) or who seek care in the same clinic (ICC=0.36). Design effects were calculated with average cluster size for both doctors and clinics. Design effects were not greater than 2, which typically do not result in overly exaggerated rejection proportions at the 5 percent level (Muthen & Satorra, 1995). Therefore, clustering was ignored for these variables in this analysis. This suggests a conservative analysis.

Missing data

Missing data were ignored, since less than 5% of missing values were present on any single variable in these data, (Kline, 2011).

Quantitative analysis

SAS 9.3 was used for all descriptive analyses. In order to normalize the distribution of skewed variables, out-of-pocket expenses, marital status, health insurance, number of individuals in the household, perceptions of financial burden, and preferences for cost of care-related communication were collapsed into categories based on distribution and/or substantive meaning.

For economic, demographic, and clinical variables, frequencies were computed for each of the categorical variables (specialty of the care-providing clinician, asthma control, frequency of asthma symptoms, types of asthma medicines prescribed, perception of financial burden, preference for cost of care-related communication, marital status, employment status, number of individuals in the household, educational attainment, household income, health insurance), and means and standard deviations were computed for continuous variables (e.g., multimorbidity, total number of medications, years since asthma diagnosis, age, out-of-pocket expenses).

Bivariate statistics (Student’s t-test for continuous variables and contingency tables with chi-squared and Fisher’s exact tests as appropriate for categorical variables) were used to examine differences in economic, demographic, and clinical characteristics between participants who reported a preference for cost of care-related communication, and those who reported not having such preferences. The main outcome of interest, preference for cost of care-related communication, was analyzed as a binary variable for bivariate analysis. Dimensions of the contingency tables were as follows: 2x2 contingency tables were computed for marital status and head of household; 3x2 tables for household income, employment status, frequency of symptoms, asthma control, and asthma medications; and 4x2 tables for educational attainment, health insurance, and specialty of care.

Structural equation models with observed variables, specifically path analysis, were used to examine indirect relationships between participants' clinical and demographic factors and their preference for cost of care-related communication via economic factors (See Figure 5.2). Path analysis was used because this technique allows for the specification of a model that attempts to explain why observed, measured, variables are correlated through other variables, and tests for these mediation effects through a series of regression models (Barron & Kenny, 1986; Kline, 2005). The exogenous variables in the model were participant clinical factors (asthma control, frequency of asthma symptoms, multimorbidity, years since asthma diagnosis, total number of medications) and demographic factors (marital status, employment status, number of individuals in the household, and educational attainment, age). The endogenous variables in the model were economic factors: household income, out-of-pocket expenses, health insurance, as well as perceptions of financial burden, and the outcome: preference for cost of care-related communication. The main outcome of interest, preference for cost of care-related communication with a health care provider, was analyzed as an ordinal categorical variable for path analysis.

Multigroup models show whether the interactions of hypothesized relationships in a model differ when stratified by another variable (Kline, 2011). To test whether health insurance (full or partial/no) had a moderating effect on the relationships in the model, a multigroup model was examined in which 1) all paths were constrained to have equal values for those with full insurance and those with partial/no insurance (fully constrained); 2) only five paths were constrained (household income → out-of-pocket expenses; household income → perceptions of financial burden → preference for cost of care-related communication; out-of-pocket expenses → perceptions of financial burden; perceptions of financial burden → preference for cost of care-related communication; household income → preference for cost of care-related communication) (partially constrained); 3) all paths were free to vary between groups (unconstrained, free model). Chi-square difference tests between pairs of models were used to see whether health insurance moderated particular paths in the model.

To assess whether the sample size (n=343) provided sufficient power to detect a close fitting model, power was calculated based on power estimates from the literature for selected levels of degrees of freedom (MacCallum, Browne, & Sugawara, 1996). With a sample size of 343 and 60 degrees of freedom, power to estimate the model was 0.96. Based on another recommended assessment of sample size, the N:q rule (sample size to parameter ratio) for maximum likelihood, a ratio of 20:1 made n=343 a sufficient sample size to estimate the proposed model (Kline, 2011).

All equations were estimated simultaneously with Mplus 6.12 software. Since there were few missing data, listwise deletion was employed where cases with missing scores on any variable are excluded from the analyses. The effective sample size (only cases with complete records) was used to estimate the path models (n=316). Power to estimate the model with the effective sample size was still 0.96 as reported above. The statistical estimator used to compute the models was weighted least square parameter estimates using a diagonal weight matrix with standard errors, and mean and variance adjusted chi-square test statistic that used a full weight matrix (WLSMV). This estimation method is recommended for binary or ordered dependent categorical variables (Muthun & Muthun, 2011; Kline, 2011). Mediation was tested through bootstrap methods. Bootstrapping is based on resampling with replacement which is done many times to compute the indirect effect in each sample and a sampling distribution. Bootstrapping in Mplus produced a standard error and a p-value with the indirect effect for both the standardized and unstandardized estimates. The number of bootstrap iterations requested was 500, which is a sufficient sample to provide reasonably stable estimates (Cheung & Lau, 2008). Correlation of parameter estimates were checked and none were found to be above 0.70 (Muthen & Muthen, 2011). Several criteria for assessing model fit were used, including the model chi-square statistic (seeking X^2 that was small and not significant), weighted root mean square residual (WRMR) (seeking WRMR closer to zero), Comparative Fit Index (CFI) (seeking CFI ≥ 0.90), and root mean square error of approximation (seeking RMSEA ≤ 0.08) (Kline, 2011; Hu & Bentler, 1999). These model fit criteria were used as a means of evaluating how close the model fit the data. Alpha values of 0.05 or less were considered significant for these analyses. Mediation was determined if indirect estimates had alpha values of 0.05 or less.

Qualitative analysis

Methods are described in full in the previous chapter. Coded questions from in-depth interviews and focus groups were used to generate themes and illustrative examples to support the quantitative analysis and describe preferences for cost of care-related communication and patient experiences with community health resources to manage the costs of asthma therapies. Comparisons and differences in themes were made between the experiences of individuals with full health insurance coverage versus partial/no insurance coverage as appropriate.

The results that follow first describe qualitative results of one aim of this study: experiences accessing community resources to address cost-related challenges. Next, bivariate results are presented between economic, demographic, and clinical characteristics and preferences for cost of care-related communication. Finally, the path analytic results are presented first describing direct relationships in the model, and then the results of the three study hypotheses. Qualitative supporting information is provided as appropriate to elaborate and provide context for the quantitative findings.

Results

Survey sample characteristics

Economic, demographic, and clinical characteristics of the total sample (n=343) are described in the previous chapter.

Qualitative sample characteristics

Economic and demographic characteristics of focus group (n=14) and in-depth interview participants (n=25) are described in the previous chapter.

Community health resources to address cost-related challenges

The results that follow address one aim of this study to describe participants' experiences accessing community resources to address cost-related challenges. Themes emerged in focus groups around participants' experiences with community health resources. Knowledge, access, and the benefits of community assistance options to address cost-related challenges with asthma therapies were noted by several participants in both the partial/no and full insurance focus groups. Participants described programs in both the county and those available through pharmaceutical companies that specifically subsidize the cost of asthma medicines or provide free medicines. One woman in the partial/no insurance group described a county program that offers discounted pharmaceuticals:

> "You know that [county name] County has a prescription plan where you can get a percentage off. If you live here, you can get it, and it's free of charge. You just got to go sign up for the card, and they'll send it to you."

A woman in the full insurance group described a local program for the uninsured:

> "They [insurance program in county]– sometimes if you don't have insurance, they'll give you insurance right on the spot. Like, you go into the office, they give you coverage, pay for your medicines and everything."

In both focus groups, participants with experience using assistance programs shared and clarified their perceptions of such programs with non-experienced participants. Perceived barriers identified in both groups to utilizing such programs included complexity of paperwork to demonstrate need, qualifications, and arduous processes to eventually obtain subsidized medicines. Experienced participants described both lack of advertising for such programs, and the relative ease of navigating sources in the current information era once they are found. One woman in the partial/no insurance group provided more context for a county program that subsidizes pharmaceuticals:

> "But it's free. It's not new. It's been around for years. It's available to anybody. Even if you have insurance, you can get it."

In the full insurance group, one woman 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."

In both focus groups, non-experienced participants were interested in accessing programs, and mentioned that they would use them if given information. Non-experienced participants were asking questions and taking notes. Experienced participants offered encouragement and information on accessing assistance programs to non-experienced participants. One woman in the partial/no insurance group noted:

> “I always go tell people, “go and apply for it- even if you think you don’t qualify. Go for it. Let them tell you no.”

In the full insurance group, one woman described the transparency of assistance programs:

> “And there are other programs out there, available. They’re in – unfortunately, they’re not always good at getting the information out to everybody. You have to search, and you have to hunt on the internet to find out the information.”

Finally, participants in the full insurance group described qualifications for programs. One woman described paper work authorization from social workers and physicians:

> “And the turnaround time is, is – most of them require a social worker, signs off the form that you have to complete. The social worker and the doctor has to write a prescription. But the turnaround time is almost 24 hours. And so, it’s really – and the application is simply just saying, “you have this chronic illness.” Um, if you have a doctor, the doctor’s name, the prescription, and then a social worker validating that all of this information is true. They don’t ask for medical records or anything. And so, it’s really quite easy.”

Another woman described the process of documenting assets and income to access programs:

> “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.”

Another woman described the relative ease of obtaining medicines once all the paperwork is in place:

> “Once you fax the information, they’ll ship the medication to you. And they’ll do it, like, um, Advair, they’ll do – as long as the doctor writes a year-worth of medication prescription. They will

> fill that every month for one year and then you have to renew your application."

Preference for cost of care-related communication

Seventy-three percent (n=251) of participants in this sample reported a preference for cost of care-related communication. Participants reported strong beliefs regarding cost of care-related communication with their health care provider. Themes from focus groups conveyed their confidence in a positive outcome expectation from such discussions by taking a proactive approach. Participants in the partial/no insurance group noted "If you ask them, they'll do it" [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."

Bivariate relationships between economic and demographic factors and preference for cost of care-related communication

Table 5.1 describes economic and demographic characteristics of participants who prefer cost of care-related communication and participants who reported not having such a preference. Economic factors that were significantly associated with a preference for cost of care-related communication included: 1) lower household income ($X^2(3) = 15.44$; $p<0.001$), and 2) more out-of-pocket expenses ($t=-2.77$, $p<0.01$). Perception of financial burden was also associated with a preference for communication ($X^2(1) = 28.17$; $p<0.001$).

Bivariate relationships between clinical characteristics and a preference for cost of care-related communication

Table 5.2 describes clinical characteristics of participants who prefer cost of care-related communication and participants who reported not having such a preference. No clinical factors were associated with a preference for cost of care-related communication.

Table 5.1: Economic and demographic characteristics of participants who do and do not have preferences for cost of care-related communication.

Variable	Total sample N=343	Preference for cost-related communication (N=251)	No preference for cost-related communication (N=91)	t or X^2
Age (mean, SD)	43.11 (14.82)	43.95 (14.91)	40.83 (14.46)	t=-1.72, *NS*
Marital status (% Married)	29% (100)	29% (73)	29% (26)	X^2 (1)=0.001, *NS*
Head of household (% yes)	67% (230)	67% (166)	70% (64)	X^2 (1)=1.13, *NS*
Number of individuals in the household				X^2 (3)=3.78, *NS*
1	38% (132)	40% (100)	35% (32)	
2	27% (92)	28% (71)	22% (20)	
3	15% (51)	14% (35)	18% (16)	
4 and more	20% (68)	18% (45)	25% (23)	
Educational attainment				X^2 (2)=1.08, *NS*
High school /GED or less	21% (70)	20% (49)	23% (21)	
Some college, associate's degree, or vocational school	47% (162)	49% (123)	43% (39)	
College or above	32% (111)	31% (79)	34% (31)	
Employment status				X^2 (2)=3.54, *NS*
Part-time	26% (87)	28% (69)	19% (17)	
Full-time	39% (131)	37% (90)	47% (41)	
No employment	35% (114)	35% (84)	34% (30)	
Household income				**X^2 (3)=15.44*****
<$20,000	42% (137)	43% (103)	40% (34)	
$20,001 - $40,000	24% (79)	28% (68)	13% (11)	
$40,001 - $60,000	18% (57)	17% (40)	20% (17)	
>$60,001	16% (52)	12% (29)	27% (23)	

Table 5.1: Continued

Variable	Total sample N=343	Preference for cost-related communication (N=251)	No preference for cost-related communication (N=91)	t or X^2
Health insurance				$^{a}X^2$ (2)=3.27, *NS*
No insurance	2% (6)	2% (4)	1% (1)	
Private	45% (153)	44% (111)	46% (42)	
Medicare only	2% (8)	2% (6)	2% (2)	
Medicare + supplemental coverage	18% (62)	20% (50)	13% (12)	
Medicaid only	27% (92)	25% (62)	33% (30)	
Other government	6% (22)	7% (18)	4% (4)	
				X^2 (1)=0.04, *NS*
[b]Full health insurance	51% (176)	52% (130)	51% (46)	
[c]Partial/no health insurance	49% (167)	48% (121)	49% (45)	
Out-of-pocket expenses (mean, SD)	$163.27 (308.27)	$185.25 (339.21)	$104.03 (190.14)	**t=-2.77****
(Range)	$0-$2,840	$0-$2,840	$0-$1,080	
Perception of financial burden (% yes)	53% (180)	61% (153)	29% (26)	**X^2 (1)=28.17*****

Student’s t-test and chi-square tests were performed on demographic variables of interest to identify differences between the groups. NS= not significant. Level of significance reported as (p-value): *p<.05, **p<.01, ***p<.001.

a. Due to low cell count, chi-square test is based on the associations between private, Medicare + supplemental coverage, and Medicaid only.
b. Partial insurance= private, no insurance, Medicare only.
c. Full insurance= Medicaid, Medicare and supplemental coverage, other government insurance.

Table 5.2: Clinical characteristics of participants who do and do not have preferences for cost of care-related communication.

Variable	Total sample N=343	Preference for cost-related communication (n=251)	No preference for cost-related communication (n=91)	P-value, t or X^2
Specialty of care				[a]X^2 (2)=1.84, *NS*
Primary care and specialist	33% (113)	34% (86)	30% (27)	
Primary care only	59% (200)	59% (147)	58% (53)	
Specialist only	6% (21)	5% (13)	9% (8)	
No doctor	2% (8)	2% (4)	3% (3)	
Years since asthma diagnosis (Mean, (SD))	18.01 (14.77)	18.46 (15.01)	16.78 (14.09)	t=-0.91, *NS*
Frequency of symptoms				X^2 (2)=2.88, *NS*
<2 days per week	61% (210)	59% (147)	68% (62)	
≥ 3 days per week	28% (95)	29% (73)	24% (22)	
Throughout the day	11% (38)	12% (31)	8% (7)	
Asthma control				X^2 (2)=2.69, *NS*
Well controlled	30% (101)	27% (69)	35% (32)	
Not well controlled	31% (107)	31% (77)	32% (29)	
Very poorly controlled	39% (135)	42% (105)	33% (30)	
Asthma medications				[b]X^2 (1)=0.00, *NS*
Controller and rescue	70% (238)	70% (174)	73% (64)	
Controller only	4% (13)	5% (12)	1% (1)	
Rescue only	19% (64)	18% (46)	20% (17)	
Allergy only	1% (1)	1% (1)	0% (0)	
Allergy and rescue only	3% (11)	3% (8)	3% (3)	
Leukotriene modifier and rescue	2% (8)	2% (5)	3% (3)	
Leukotriene modifier only	1% (1)	1% (1)	0% (0)	
Total number of medications (Mean, (SD))	5.32 (2.88)	5.48 (2.83)	4.91 (2.99)	t=-1.63, *NS*
Total number of other chronic conditions (Mean, (SD))	3.65 (2.57)	3.78 (2.59)	3.31 (2.52)	t=-1.48, *NS*

Chi-square tests were performed on clinical variables of interest to identify differences between the groups. NS= not significant. Level of significance reported as (p-value): *p<.05, **p<.01, ***p<.001.

a. Due to low cell count, chi-square test is based on the associations between primary care and specialist, primary care only, and specialist only.
b. Due to low cell count, chi-square test is based on the associations controller and rescue, and rescue only.

Path analytic results

A path model that allowed for the estimation of multiple equations simultaneously was computed, so that associations between multiple predictor and outcome variables could be assessed in the same model. The path analytic results address the second aim of this study to explore indirect relationships between patients' clinical and demographic characteristics and preference for cost of care-related communication. The results that follow first describe direct relationships in the model and then address the study hypotheses: 1) the relationship between demographic factors and preference for cost of care-related communication will be mediated through household income, health insurance, out-of-pocket expenses, and perceptions of financial burden, 2) the relationship between clinical factors and preference for cost of care-related communication will be mediated through out-of-pocket expenses and perceptions of financial burden, and 3) Health insurance will have a moderating effect on the relationships in hypotheses 1 and 2.

Direct effects in the path model of patient factors on preferences for cost of care-related communication and economic mediators

The final fit of the model in Figure 5.2 was based on recommended values of several criteria recommended from the literature. The fit criteria based on the RMSEA suggested that model's correspondence to the data was good (X^2=107.212, df=59, p<0.001; CFI= 0.87, RMSEA= 0.051, 90% CI: 0.035 to 0.066; WRMR=1.11) (MacCallum, Browne & Sugawara, 1996). Good fit implies that a model is plausible. However, no set of fit statistics are definitive or provide a gold standard whether to retain or reject a model (Kline, 2011). Kenny (2012) suggests that the CFI should not be computed if the RMSEA of the null model is less than 0.158 or otherwise one will obtain too small a value of the CFI (Kenny, 2012). CFI is sensitive to the number of the parameters in the model (Kenny, 2012), which may be one plausible reason why the CFI was observed to be slightly below the recommended threshold in this study, but other fit statistics such as the RMSEA suggested that the model fit was good. The model was theoretically sound and provided a vehicle for testing the hypotheses of this study. The model serves as an approximation of hypothesized processes.

Forty-two percent of the variance in the model was explained by out-of-pocket expenses, while 52% was explained by household income, 53% explained by health insurance, 21% explained by perception of financial burden, and 18% of the variance in the model explained by preferences for cost of care-related communication.

Table 5.3 shows direct effects in the path model of clinical and demographic factors on preferences for cost of care-related communication and economic mediators. To ease the comparison of coefficients, standardized coefficients for the measurement model are provided, in addition to the significance associated with the unstandardized estimate: (unstandardized estimate (standard error) standardized estimate) (Kline, 2011). Participants who reported perceptions of financial burden were more likely to report a preference for cost of care-related communication compared to participants who did not report these perceptions ($\beta=0.408$ (SE=0.086), 0.417, $p<0.001$). A significant, direct relationship was not found for household income and a preference for cost of care-related communication.

Clinical factors directly associated with out-of-pocket expenses included 1) multimorbidity: participants with more chronic conditions had fewer out-of-pocket expenses ($\beta= -0.145$ (SE=0.062), -0.285, $p<0.05$), and 2) total number of medications: participants with more medications had more out-of-pocket expenses ($\beta=0.136$ (SE=0.059), 0.294, $p<0.05$).

Household income was directly related to health insurance. Compared to individuals with more income, those who had less household income were more likely to have full insurance coverage (e.g. Medicare and supplemental coverage, Medicaid, other government sponsored insurance) (β= -0.674 (SE=0.148), -0.661, p<0.001). Compared to individuals with partial/no health insurance coverage (e.g. private health insurance, Medicare only, and no insurance), individuals with full insurance coverage had fewer out-of-pocket expenses (β= -0.533 (SE=0.101), -0.596, p<0.001).

Indirect effects in the path model of clinical and demographic factors on preferences for cost of care-related communication

Table 5.4 shows indirect effects in the analytic model of clinical and demographic factors on preferences for cost of care-related communication. Standardized estimates with bootstrapped standard errors are reported here. Perceptions of financial burden mediated the relationship between out-of-pocket expenses and a preference for cost of care-related communication. More out-of-pocket expenses indicated more frequent perceptions of financial burden, and more frequent perceptions of financial burden indicated a higher preference for cost of care-related communication (β= 0.207 (SE=0.061), p<0.001).

Table 5.3: Direct effects in the path model of clinical and demographic factors on preferences for cost of care-related communication and economic mediators.

Predictors	Out-of-pocket expenses	Household income	Health insurance (Full Insurance)	Perception of financial burden	Preferences for cost of care-related communication
	Unst. (SE) Stn.	Unst. (SE) Stn.	Unst. (SE) Stn.	Unst. (SE) Stn.	Unst. (SE) Stn.
CLINICAL FACTORS					
Multimorbidity	-0.145* (0.052) -0.285				
Asthma control					
Not Well Controlled	0.241 (0.222) 0.085				
Poorly Controlled	0.179 (0.241) 0.067				
Frequency of asthma symptoms					
Three or more days per week	0.108 (0.214) 0.037				
Daily	0.183 (0.276) 0.044				
Years since diagnosis	0.002 (0.006) 0.023				
Total number of medications	0.136*(0.048) 0.294				
ECONOMIC AND DEMOGRAPHIC FACTORS					
Age		0.016** (0.006) 0.162	-0.022*** (0.008) -0.222		
Marital status (Married)		1.086*** (0.189) 0.343			
Employment status					
Part time		0.693** (0.185) 0.213			
Full time		1.283*** (0.198) 0.437			
Number of individuals in household		-0.014 (0.079) -0.01			
Educational attainment					
Some college		0.806*** (0.179) 0.280			
College and above		1.52*** (0.194) 0.500			

Table 5.3: Continued

Predictors	Out-of-pocket expenses	Household income	Health insurance (Full Insurance)	Perception of financial burden	Preferences for cost of care-related communication
	Unst. (SE) Stn.	Unst. (SE) Stn.	Unst. (SE) Stn.	Unst. (SE) Stn.	Unst. (SE) Stn.
Household income			-0.674*** (0.101) -0.661	-0.087 (0.069) -0.111	-0.076 (0.057) -0.099
Health insurance (Full Insurance)	-0.533*** (0.091) -0.59				
Out-of-Pocket expenses				0.426*** (0.080) 0.496	
Perception of financial burden					0.408*** (0.077) 0.417

P<0.05*, P<0.01**, P<0.001***; Unst.= unstandardized estimates, SE= standard error, Stn.= standardized estimate; Reference categories- Asthma control- well controlled, Frequency of asthma symptoms- 2 days or less, Marital status- single, Employment status- unemployed, Educational attainment- high school or less/GED, Health insurance- partial insurance. Partial insurance= private, no insurance, Medicare only. Full insurance= Medicaid, Medicare and supplemental coverage, other government insurance.

Income and preference for communication were related through the following pathway: health insurance mediated the relationship between income and out-of-pocket expenses, out-of-pocket expenses mediated the relationship between health insurance and perception of financial burden, perception of financial burden mediated the relationship between out-of-pocket expenses and a preference for cost of care-related communication. More income indicated a higher likelihood of having partial/no health insurance, partial/no health insurance indicated more out-of-pocket expenses, more out-of-pocket expenses indicated more frequent perceptions of financial burden, and more frequent perceptions of financial burden indicated a higher preference for cost of care-related communication (β= 0.082 (SE=0.031), $p<0.01$).

Health insurance and preference for communication were related through the following pathway: out-of-pocket expenses mediated the relationship between health insurance and perceptions of financial burden, and perception of financial burden mediated the relationship between out-of-pocket expenses and a preference for communication. Having full insurance coverage indicated fewer out-of-pocket expenses, fewer out-of-pocket expenses indicated less frequent perceptions of financial burden, and less frequent perceptions of financial burden indicated a lower preference for cost of care-related communication (β= -0.123 (SE=0.043), $p<0.001$).

Table 5.4: Indirect effects in the path model of clinical and demographic factors on preferences for cost of care-related communication.

Path	Unstandardized (S.E.)	Standardized (S.E.)	Sum of indirect, Unst. (S.E)	Sum of indirect, Stn. (S.E.)
Out-of-pocket expenses → perception of financial burden → preferences for cost of care-related communication	0.174 (0.051)***	0.207 (0.061)***		
CLINICAL FACTORS				
Multimorbidity → out-of-pocket expenses → perception of financial burden → preferences for cost of care-related communication	-0.025 (0.012)*	-0.059 (0.028)		
Not well controlled asthma → out-of-pocket expenses → perception of financial burden → preferences for cost of care-related communication	0.042 (0.047)	0.018 (0.019)		
Poorly controlled asthma→ out-of-pocket expenses → perception of financial burden → preferences for cost of care-related communication	0.031 (0.057)	0.014 (0.025)		
Three or more days of symptoms→ out-of-pocket expenses → perception of financial burden → preferences for cost of care-related communication	0.019 (0.041)	0.008 (0.017)		
Daily symptoms → out-of-pocket expenses → perception of financial burden → preferences for cost of care-related communication	0.032 (0.060)	0.009 (0.017)		

Table 5.4: Continued

Path	Unstandardized (S.E.)	Standardized (S.E.)	Sum of indirect, Unst. (S.E)	Sum of indirect, Stn. (S.E.)
Years since diagnosis → out-of-pocket expenses → perception of financial burden → preferences for cost of care-related communication	0.00 (0.001)	0.005 (0.016)		
Total medications → out-of-pocket expenses → perception of financial burden → preferences for cost of care-related communication	0.024 (0.011)*	0.061 (0.027)*		
ECONOMIC AND DEMOGRAPHIC FACTORS				
Age → health insurance (Full) → out-of-pocket expenses → perception of financial burden → preferences for cost of care-related communication	0.002 (0.001)	0.027 (0.016)		
Age → household income → perception of financial burden → preferences for cost of care-related communication	-0.001 (0.001)	-0.007 (0.009)		
Age → household income → preferences for cost of care-related communication	-0.001 (0.001)	-0.016 (0.016)		
Health insurance (Full) → out-of-pocket expenses → perception of financial burden → preferences for cost of care-related communication	-0.093 (0.032)**	-0.123 (0.043)**		
Household income → health insurance (Full) → out-of-pocket expenses → perception of financial burden → preferences for cost of care-related communication	0.062 (0.023)**	0.082 (0.031)**		
Marital status (Married) → preferences for cost of care-related communication			-0.053 (0.081)	-0.022 (0.033)
Marital status (Married) → household income → preferences for cost of care-related communication	-0.083 (0.076)	-0.034 (0.031)		

Table 5.4: Continued

Path	**Unstandardized (S.E.)**	**Standardized (S.E.)**	**Sum of indirect, Unst. (S.E)**	**Sum of indirect, Stn. (S.E.)**
Marital status (Married) → household income → health insurance (Full) → out-of-pocket expenses → perception of financial burden → preferences for cost of care-related communication	0.068 (0.029)*	0.028 (0.012)*		
Marital status (Married) → household income → perception of financial burden → preferences for cost of care-related communication	-0.038 (0.043)	-0.016 (0.018)		
Part time employment → preferences for cost of care-related communication			-0.034 (0.050)	-0.014 (0.020)
Part time employment → household income → health insurance (Full) → out-of-pocket expenses → perception of financial burden → preferences for cost of care-related communication	0.043 (0.023)	0.017 (0.009)		
Part time employment → household income → preferences for cost of care-related communication	-0.053 (0.049)	-0.021 (0.019)		
Part time employment → Hhousehold income → perception of financial burden → preferences for cost of care-related communication	-0.025 (0.028)	-0.010 (0.011)		
Full time employment → preferences for cost of care-related communication			-0.063 (0.093)	-0.028 (0.041)
Full time employment → household income → health insurance (Full) → out-of-pocket expenses → perception of financial burden → preferences for cost of care-related communication	0.080 (0.033)**	0.036 (0.015)**		

Table 5.4: Continued

Path	Unstandardized (S.E.)	Standardized (S.E.)	Sum of indirect, Unst. (S.E)	Sum of indirect, Stn. (S.E.)
Full time employment → household income → preferences for cost of care-related communication	-0.097 (0.088)	-0.043 (0.039)		
Full time employment → household income → perception of financial burden → preferences for cost of care-related communication	-0.045 (0.050)	-0.020 (0.022)		
Number of individuals in household → preferences for cost of care-related communication			0.001 (0.006)	0.001 (0.007)
Number of individuals in household → household income → health insurance (Full) → out-of-pocket expenses → perception of financial burden → preferences for cost of care-related communication	-0.001 (0.006)	-0.001 (0.006)		
Number of individuals in household → household income → preferences for cost of care-related communication	0.001 (0.008)	0.001 (0.008)		
Number of individuals in household → household income → perception of financial burden → preferences for cost of care-related communication	0.000 (0.004)	0.001 (0.004)		
Some college → preferences for cost of care-related communication			-0.039 (0.060)	-0.018 (0.027)
Some college → household income → health insurance (Full) → out-of-pocket expenses → perception of financial burden → preferences for cost of care-related communication	0.050 (0.025)*	0.023 (0.011)*		

Table 5.4: Continued

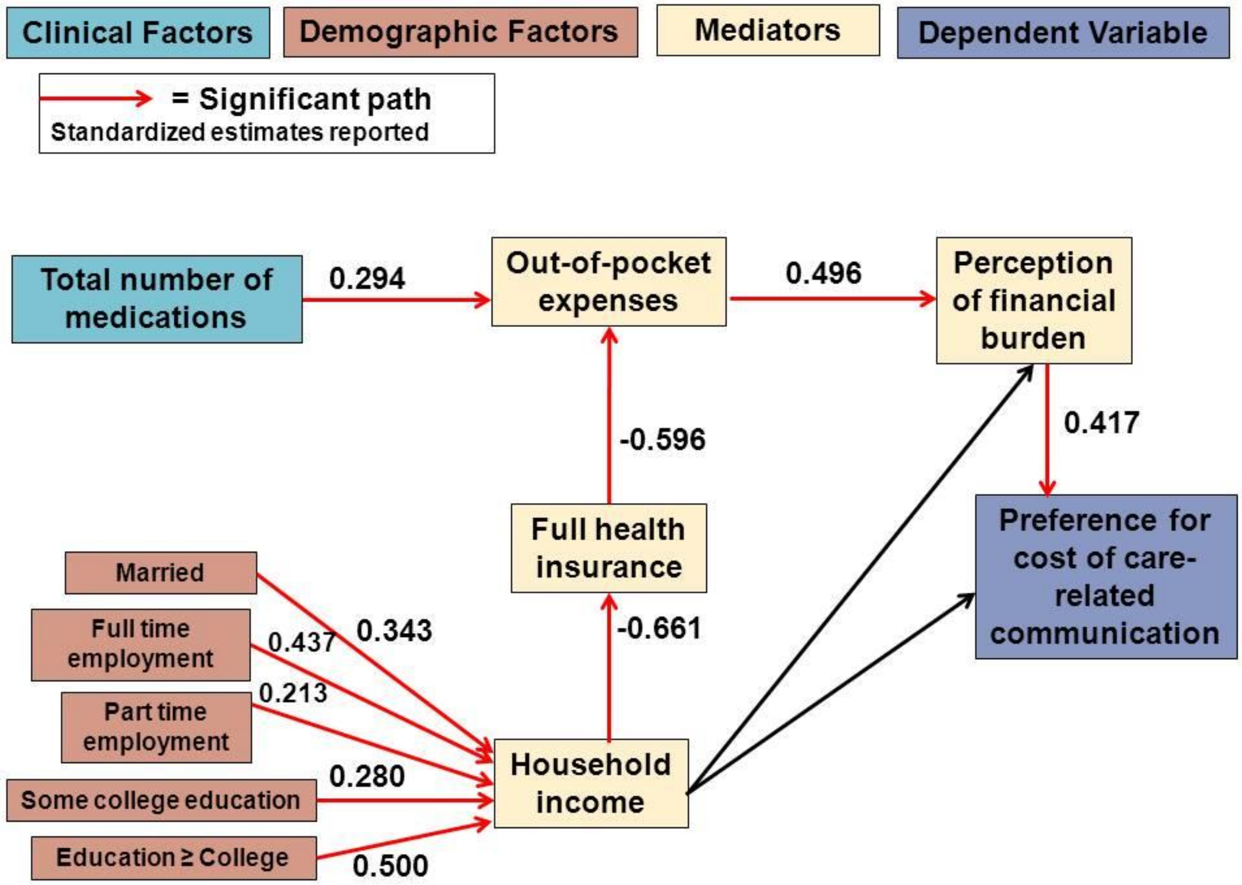
Path	Unstandardized (S.E.)	Standardized (S.E.)	Sum of indirect, Unst. (S.E)	Sum of indirect, Stn. (S.E.)
Some college → household income → preferences for cost of care-related communication	-0.061 (0.060)	-0.028 (0.027)		
Some college → household income → perception of financial burden → preferences for cost of care-related communication	-0.029 (0.032)	-0.013 (0.015)		
College and above → preferences for cost of care-related communication			-0.074 (0.11)	-0.032 (0.048)
College and above → household income → health insurance (Full) → out-of-pocket expenses → perception of financial burden → preferences for cost of care-related communication	0.095 (0.04)**	0.041 (0.017)**		
College and above → household income → preferences for cost of care-related communication	-0.116 (0.108)	-0.050 (0.046)		
College and above → household income → perception of financial burden → preferences for cost of care-related communication	-0.054 (0.059)	-0.023 (0.025)		

P<0.05*, P<0.01**, P<0.001***; Unst.= unstandardized estimates, SE= standard error, Stn.= standardized estimate; Reference categories- Asthma control- well controlled, Frequency of asthma symptoms- 2 days or less, Marital status- single, Employment status- unemployed, Educational attainment- high school or less/GED, Health insurance- partial insurance. Partial insurance= private, no insurance, Medicare only. Full insurance= Medicaid, Medicare and supplemental coverage, other government insurance.

The results also partially supported hypothesis 1 for marital status, employment status, and educational attainment through the following pathway: household income mediated the relationship between each significant demographic factor (being married, full time employment, and some college or college and above education) and health insurance, health insurance mediated the relationship between household income and out-of-pocket expenses, and perception of financial burden mediated the relationship between out-of-pocket expenses and preference for communication. Being married as opposed to single indicated more income, more income indicated a higher likelihood of having partial/no health insurance, partial/no health insurance indicated more out-of-pocket expenses, more out-of-pocket expenses indicated more frequent perceptions of financial burden, and more frequent perceptions of financial burden indicated a higher preference for communication ($\beta = 0.028$ (SE=0.012), $p<0.05$). Some college ($\beta = 0.023$ (SE=0.011), $p<0.05$) and college education and above ($\beta = 0.041$ (SE=0.017), $p<0.01$) as opposed to less than a high school education indicated more income, more income indicated a higher likelihood of having partial/no health insurance, partial/no health insurance indicated more out-of-pocket expenses, more out-of-pocket expenses indicated more frequent perceptions of financial burden, and more frequent perceptions of financial burden indicated a higher preference for communication. Full time employment as opposed to no employment indicated more income, more income indicated a higher likelihood of having partial/no health insurance, partial/no health insurance indicated more out-of-pocket expenses, more out-of-pocket expenses indicated more frequent perceptions of financial burden, and more frequent perceptions of financial burden indicated a higher preference for communication ($\beta = 0.036$ (SE=0.015), $p<0.01$).

The results that follow address what clinical factors are indirectly associated with a preference for communication. The results partially supported hypothesis 2 for total number of medications through the following pathway: 1) out-of-pocket expenses mediated the relationship between total number of medications and perception of financial burden, and perception of financial burden mediated the relationship between out-of-pocket expenses and preference for communication. More medications indicated more out-of-pocket expenses, more out-of-pocket expenses indicated more frequent perceptions of financial burden, and more frequent perceptions of financial burden indicated a higher preference for communication ($\beta = 0.061$ (SE=0.027), $p<0.05$). All significant paths with standardized estimates are seen in Figure 5.3.

Figure 5.3: Path model depicting estimates of indirect relationships between clinical and demographic factors and preferences for cost of care-related communication.



Differences by full versus partial health insurance coverage

Economic, demographic, and clinical differences between individuals with full versus partial/no insurance were described in the previous chapter.

The results seen in Table 5.5 supported hypothesis 3. Adding the cross-group equality constraints revealed evidence that the relationships of interest in the model varied by health insurance status (ΔX^2 (5) = 30.22, p<0.001); overall, there was strong support that health insurance status moderated the relationships between household income, out-pocket expenses, perceptions of financial burden, and preferences for communication.

Table 5.5: Difference testing: multiple group model to examine the moderated effects of health insurance (full vs. partial/no coverage*) on the relationships in the path model.

Hypothesis Description	**X^2**	**df**	**RMSEA**	**Models compared**	**ΔX^2 *****	**Δ df**	**p-value**
1. Free Model	105.35	86	0.038	--	--	--	--
2. 5 regression constraints (partially constrained)**	131.49	91	0.053	2 & 1	30.225	5	**<0.001**
3. Fully constrained model	148.66	105	0.051	3 & 2	19.507	14	0.1465

*Full insurance= Medicaid, Medicare and supplemental coverage, other government insurance; Partial/no insurance= private, no insurance, Medicare only.

** 5 constrained paths: 1) household income → out-of-pocket expenses, 2) household income → perceptions of financial burden → preferences for cost of care-related communication, 3) out-of-pocket expenses → perceptions of financial burden, 4) perceptions of financial burden → preferences for cost of care-related communication, 5) household income → preferences for cost of care-related communication.

***Since the estimator used to compute the models was a mean- and variance adjusted chi-square test statistic that uses a full weight matrix (WLSMV), special procedures were used to calculate differences in chi-square, specifically the difftest procedure in Mplus.

Table 5.6 examines differences between individuals with full and partial/no insurance with estimates of between-group differences between the effects of household income, out-of-pocket expenses, and perceptions of financial burden on preferences for communication. To ease the comparison of coefficients, standardized coefficients for the measurement model are provided, in addition to the significance associated with the unstandardized estimate: (unstandardized estimate (standard error) standardized estimate) (Kline, 2011). For the full insurance group, greater income was associated with more out-of-pocket expenses (β= 0.299 (SE=0.089), 0.341, $p<0.001$); this relationship was not observed for the partial/no insurance group. For both the full (β= 0.596(SE=0.130), 0.554, $p<0.001$) and partial/no insurance groups (β= 0.305 (SE=0.09), 0.318, $p<0.01$), more out-of-pocket expenses was associated with increased perceptions of financial burden. For both the full (β= 0.262(SE=0.091), 0.295 $p<0.001$) and partial/no insurance groups (β= 0.553 (SE=0.13), 0.493, $p<0.001$), greater perceptions of financial burden was associated with more of a preference for communication. All significant paths with standardized estimates are seen in Figure 5.4.

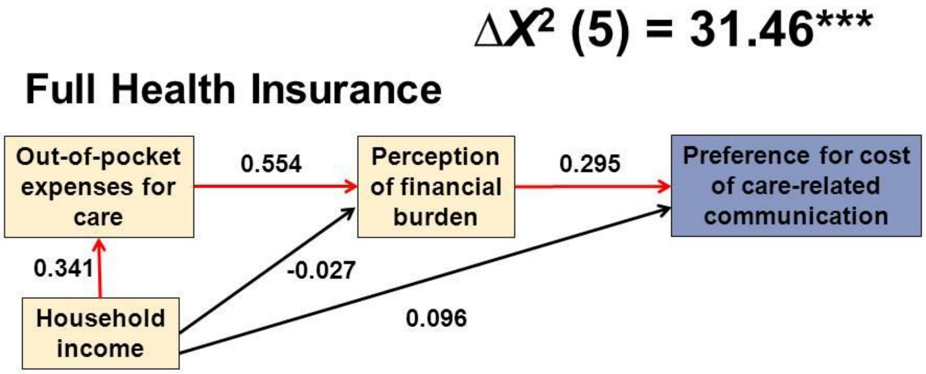
The partially constrained model accounted for similar variance among the full insurance group compared to the partial/no insurance group for out of pocket expenses (21% for partial/no insurance, 19% for full insurance), but less variance for the full insurance group compared to the partial/no insurance group for household income (43% for partial/no insurance, 38% for full insurance), and preferences for cost of care-related communication (32% for partial/no insurance, 11% for full insurance). More variance was observed for the full insurance group compared to the partial/no insurance group for perceptions of financial burden (15% for partial/no insurance, 30% for full insurance).

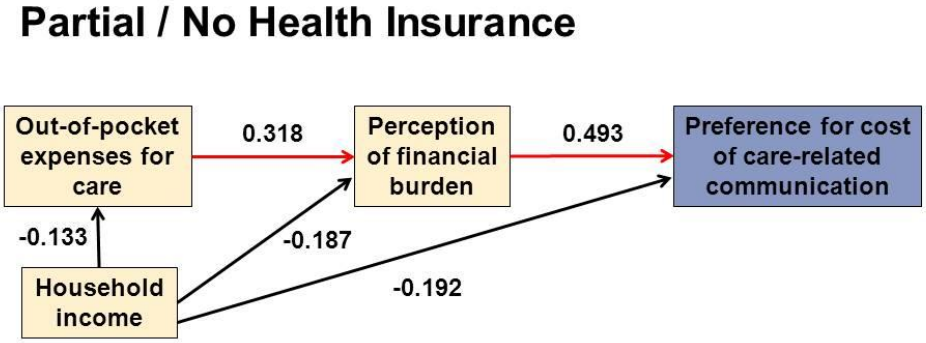
Table 5.6: Estimates of between-group differences: multiple group model to examine the moderated effects of health insurance (full vs. partial/no coverage*) on the relationships in the path model.

Hypothesis Description	**Full insurance**	**Partial/no insurance**
	Unst. (SE) Stn.	**Unst. (SE) Stn.**
Household income → out-of-pocket expenses	0.299*** (0.089) 0.341	-0.113 (0.86) -0.133
Household income → perceptions of financial burden	-0.026 (0.097) -0.027	-0.152 (0.083) -0.187
Out-of-pocket expenses → perceptions of financial burden	0.596*** (0.130) 0.554	0.305** (0.09) 0.318
Perceptions of financial burden → preferences for cost of care-related communication	0.262** (0.091) 0.295	0.553*** (0.134) 0.493
Household income → preferences for cost of care-related communication	0.080 (0.092) 0.096	-0.175 (0.094) -0.192

Level of significance reported as (p-value): *p<.05, **p<.01, ***p<.001; Unst.= unstandardized estimates, SE= standard error, Stn.= standardized estimate. Partial insurance= private, no insurance, Medicare only. Full insurance= Medicaid, Medicare and supplemental coverage, other government insurance.

Figure 5.4: Estimates of between-group differences: multiple group model to examine the moderated effects of health insurance (full vs. partial/no coverage*) on the relationships in the path model.





Discussion

This study examined 1) indirect relationships between demographic and clinical characteristics and their preferences for cost of care-related communication within a high-risk population with asthma, and 2) experiences accessing community assistance programs. This is the first study to examine these relationships in an adult population with asthma. Three fourths of the sample reported a preference for cost of care-related communication, which is consistent with other work in the general medicine literature (Tseng et al., 2010; Donahue et al., 2009; Tseng et al., 2007; Alexander et al., 2003). Bivariate analyses showed more individuals with low income, high out-of-pocket expenses, and who reported perceptions of financial burden also reported a preference for communication. These findings reinforce previous work that has shown economic and demographic differences among individuals who report preferences for cost of care-related communication (Tseng et al., 2010; Tseng et al., 2007; Alexander et al., 2004).

This study went a step further from previous work, and supported hypotheses that household income, type of health insurance, out-of-pocket expenses, and perceptions of financial burden explained relationships through which marriage, more education, and full time employment influenced a preference for communication. Total number of medications influenced a preference for communication via out-of-pocket expenses and subsequent perceptions of financial burden. No direct relationships where found between household income and preferences for communication; household income influenced a preference for communication through health insurance, out-of-pocket expenses, and perception of financial burden.

Individuals whose characteristics may suggest more economic security, actually had high preferences for cost of care-related communication. As discussed in the previous chapter, the complex relationships between rising costs, policies, and other sectors of the economy affected by the current economic climate may complicate the provision of affordable health care coverage, and factors that conventionally contribute to social mobility and economic security. As a result, a need to discuss out-of-pocket costs associated with care recommendations may heighten.

This study found that perceptions of financial burden were associated with a preference for cost of care-related communication for people with full and partial or no health insurance coverage. These findings reinforce the fact that individuals with all types of health insurance plans and those without health insurance perceive financial burden due to their out-of-pocket expenses, and consequently prefer to discuss the cost of their care with their health care provider. Although the common perception is that full insurance plans (as categorized in this study as Medicare and supplemental coverage, Medicaid, and other government insurance) provide comprehensive coverage, some individuals under such plans perceive out-of-pocket expenses as burdensome and a preference for communication is apparent.

The qualitative findings suggested that among individuals with asthma, community health programs that offer assistance with the cost of care and therapies are being utilized by some participants; however, barriers to accessing information on programs may preclude some people to be aware of their full range of options. Barriers to accessing and navigating online information tools 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 health care provider, cost of care-related communication with a patient appears essential for them to obtain low-cost options.

There are several limitations in this study that should be noted in considering the implications of these findings. The concurrent mixed methods approach revealed limitations in terms of the ability to use qualitative data to clarify the quantitative approaches. The opportunity to use qualitative data to inform the measures and specify more complex pathways in the analytic model would have provided a more adequate assessment of the relationships of interest, and perhaps fit the model closer to the data.

Qualitative investigations revealed that participants use community health resources to assist them with their out-of-pocket expenses. Quantitative assessments on use of such programs were not available in the data source. The use of such resources may influence preferences for cost of care-related communication, and provides opportunities for future studies to quantify use of programs that are helpful.

SEM procedures, including path analysis, require measures to have strong psychometric properties to ensure stable statistical estimation (Kline, 2011). Data were self-reported, therefore, some responses may not reflect actual preferences. Existing tools to measure out-of-pocket expenses with health care and perceptions of financial burden may be conceptually inadequate. The measure concerning household composition may not have captured non-family members or other members of a participant’s social network dependent on the household income. The measure to assess out-of-pocket expenses only assessed the cost associated with medicines, and may not have captured all of the out-of-pock expenses participants may incur with their asthma-related disease management. Therefore participants’ out-of-pocket expenses in this study may be underreported. Few measurement tools aside from self-report recall exist to ascertain out-of-pocket expenses. Diary approaches may usefully mitigate the limitations associated with recall. They may also provide a comprehensive picture of out-of-pocket expenses associated with asthma including lost work time, and expenses related to transportation, health care visits, and environmental modifications.

Given changes in federal and state health insurance programs from an unpredictable economy and the recent passage of the Patient Protection and Affordable Care Act (PPACA), the classification of types of health insurance in broader categories of “full” and “partial/no” insurance may not reflect these evolving trends. Some private insurance plans are also more comprehensive than government sponsored insurance or perceived as such, however data on the comprehensiveness of private insurance plans were not available in the data sources. Additionally, the asthma-related formularies for the types of health insurance surveyed may be different than the amount of broader coverage plans typically provide. Additionally, the asthma-related formularies for the surveyed types of health insurance may differ from the amount of broader coverage plans typically provide.

The ability to note subtle distinctions in variables collapsed via Likert response scales or response distribution may have been lost. To address this, collapsed variables were checked to see if they achieved similar results when collapsed differently around cut-points. Results demonstrated similar results in the same direction.

The data were cross-sectional; therefore, the true direction of association between some variables may not be easily discerned. Longitudinal data would provide more opportunities to examine reciprocal or non-recursive relationships between preferences for cost of care-related communication, perceptions of financial burden, and economic, demographic, and clinical characteristics.

Since this study utilized secondary data for the item-specific survey and in-depth interview data, limitations were that items may have been measured differently than anticipated, or limited to what already exists or may be incomplete. With the qualitative data collection obtained through focus groups, social desirability and the group format may have precluded individuals from sharing their true preferences for communication about their out-of-pocket expenses.

Finally, the study sample comprised African American women receiving care in Southeast Michigan. As a result, findings may not be generalizable to all women or all adults with asthma or those receiving care in other regions. Because inclusion criteria for the study required participants to receive care for their asthma, the number of individuals who report not having a health care provider for their asthma may be greater than reported here.

Despite these limitations, this study has strengths. Both qualitative and quantitative investigations revealed that a preference for cost of care-related communication is quite high and evident despite factors that may suggest an individuals' ability to access or bear the costs associated with their care. This study revealed that some individuals with asthma are utilizing assistance programs in the community to manage their out-of-pocket expenses, while others are unaware of such options. Lastly, this study made a case for why cost of care-related communication is an important intervention to potentially mitigate patients' financial burden: 1) it is preferred by patients, and 2) dialogue between clinician and patient appears necessary in order for patients to access community assistance programs.

Implications

Findings from this study have a number of implications for health education interventions and clinical practice.

Health Education Interventions

Health education interventions may be designed, with particular attention to health literacy and numeracy, to provide more awareness of assistance programs and outreach to individuals with chronic conditions, especially vulnerable populations. Such interventions may also increase ease of navigating community assistance programs, and as well as navigating new information systems that accompany reforms from the Patient Protection and Affordable Care Act. These new systems include the health insurance exchanges, coverage options for public health insurance programs, applying for federal subsidies for out-of-pocket expenses, and public reporting of quality metrics of health care providers.

Clinical practice

As established in the previous chapter, clinicians provide therapeutic recommendations and play an instrumental role in facilitating chronic disease management. The findings presented here provide support that patient preference for communicating their out-of-pocket expenses with their health care provider is high. Improving communication between clinician and patient is of interest to many stakeholders, as reforms of provider incentives with the Patient Protection and Affordable Care Act move toward rewarding clinicians for prevention and the quality of care they deliver. The findings supported that cost of care-related communication is desired. This may be linked to satisfaction, which is an important outcome to clinicians, payers, and the viability of health systems.

Clinical implications of this work include the ability for health care providers to recognize that a wide-range of patients may have a high preference to discuss the cost of their care. Providers may be better equipped to target their communication efforts in assisting their patients with financial burden and availing them to their full range of options. They may especially inquire about the total number of medications their patients are prescribed, and whether their cumulative out-of-pocket expenses are affecting asthma management. This may provide a window of opportunity to elicit information to engage in potentially sensitive discussions regarding affordability.

Given the limited time often afforded to clinicians to spend with their patients, utilizing visit time with approaches that have the greatest impact on patients' health outcomes becomes critical. The next chapter will explore how often the communication of cost between clinician and patient actually occurs, options offered to patients that they find helpful, and how cost of care-related communication influences asthma self-management behaviors and asthma-related urgent care use. Exploring these questions will allow for a better understanding of whether patient preferences for cost of care-related communication are actually being met.

Conclusion

The majority of women with asthma report a preference to discuss cost with their clinician. Individuals with high out-of-pocket expenses, and who perceive financial burden are more likely to report a preference, unrelated to the complexity or control of their asthma. These preferences are evident despite factors that may suggest an individuals' ability to access or bear the costs associated with their care. Information on available programs to assist with cost may not be accessible to all patients, and access often requires documentation from a clinician. Given the high percentage of women desiring cost-of-care discussion, clinicians may be sensitive to their preferences and attending to needs that may impact their disease management.

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CHAPTER 6

COST OF CARE-RELATED COMMUNICATION IN THE CLINICAL ENCOUNTER AND ASTHMA OUTCOMES AMONG WOMEN WITH ASTHMA

Abstract

Many adults with asthma report financial burden associated with managing their conditions, and a preference to discuss the cost of care with a clinician (cost of care-related communication) is high. The purpose of this study was to examine 1) direct and indirect relationships between cost of care-related communication, self-management behaviors, and asthma outcomes, and 2) options offered to women by health care providers that have proven helpful in managing asthma-related expenses. Baseline data were collected through standardized telephone interviews from 343 African American women seeking services for asthma in the Southeast Michigan. Additional qualitative data were collected through sub-samples via two focus groups (n=14) and in-depth interviews (n=25). Coded transcripts were analyzed for themes to provide supporting information. The relationship between communication and self-management behaviors was assessed with multivariate linear regression models. The relationships between cost of care-related communication and asthma outcomes (asthma-related urgent office visits, emergency department visits, and hospitalizations) were examined through a hypothesized mediator (asthma control) using structural equation models. The mean age of participants was 42.8 years (SD=14.82). Thirty-nine percent (n=134) reported that they discuss the cost of their care with their clinician, and within this group, 75% (n=100) initiate the discussion. Helpful options offered to participants by their health care providers included free samples. No significant associations were found between self-management behaviors and cost of care-related communication when adjusted for confounders. No indirect, significant relationships were found for cost of care-related communication and asthma-related urgent office visits, emergency department visits, and hospitalizations when adjusted for confounders. Less than half of the sample reported discussing the cost of their asthma care with their health care provider, although more than three quarters of participants reported preferences for such discussions. The majority of patients initiate the conversation. Data and research design limitations may have precluded finding significant associations between cost of care-related communication, and self-management behaviors and asthma-related urgent care use. Despite these limitations, patients are interested in low-cost options and a venue for addressing their concerns with a care provider, therefore a greater understanding is needed in how to effectively and efficiently integrate these conversations into the delivery of health care.

Introduction

Asthma is a prevalent chronic condition where adverse health outcomes are common and associated costs are high (Akinbami, Moorman, & Liu, 2011). The management of chronic diseases like asthma requires an ongoing partnership over months and years between physicians and families in order to actively monitor the therapeutic regimen and make adjustments to the treatment plan to gain optimum control of the condition (Clark et al., 1995). Patients may perceive management as financially burdensome. One-third of adults in the general population who have asthma report financial burden associated with managing their condition, and discussion of the cost of care (cost of care-related communication) occurs infrequently in clinical encounters (Kaiser Family Foundation, 2005; Alexander, Casalino, & Meltzer, 2003). Cost of care-related communication is the dialogue in the clinical encounter concerning the direct, out-of-pocket cost of therapeutic recommendations (e.g. medications, devices, environmental modifications, etc.) for illness management a patient incurs. General communication plays an integral role in shaping the relationship between physicians and patients, and has been shown to affect the process and outcomes of care in asthma (Clark et al., 2008; Diette & Rand, 2007; Roter & Hall, 2006). Cost of care-related communication may demonstrate similar relationships, although this has not been examined.

Among studies that have examined how often cost of care-related communication occurs in the clinical encounter, findings consistently show that this discussion occurs only infrequently: less than 50% of the time as reported by patients, health care providers, and objective observation (Tseng et al., 2010; Neumann, Palmer, Nadler, Fang, & Ubel, 2010; Newcomb, McGrath, Covington, Lazarus, & Janson, 2010; Beard et al., 2010; Tseng et al., 2009; Patel, Coffman, Tseng, Clark, & Cabana, 2009; Benedetti et al., 2008; Tseng et al., 2007; Wilson et al., 2007; Beran, Laouri, Suttorp, & Brook, 2007; Shrank et al., 2006(a); Shrank et al., 2006(b); Tarn et al., 2006; Heisler, Wagner, & Piette, 2004; Piette, Heisler, & Wagner, 2004(a); Piette, Heisler, & Wagner, 2004(b); Alexander et al., 2003). In a sample of over 1,000 Medicare beneficiaries, patient self-report found that although over 90% of health care providers chose medications for patients, less than 50% offered choices and less than 20% inquired about affordability or discussed prices (Tseng et al., 2007). When communication does occur, studies with predominately non-Hispanic white patients show that these discussions occur more frequently with patients burdened by out-of-pocket expenses, seen in community practice, cutting back on medications, and patients with low income, and low educational attainment (Beard et al., 2010;

Tarn et al., 2006; Heisler et al., 2004; Piette et al., 2004(a); Alexander et al., 2003). Findings in existing studies are mixed concerning who initiates cost of care-related discussions, with self-report studies demonstrating that patients initiate discussion of cost more frequently than providers (Beran et al., 2007; Tseng et al., 2007), while objective observation has shown initiation of such conversations to occur equally frequently between patients and clinicians (Beard et al., 2010). How often cost of care-related communication occurs among individuals with asthma or a high-risk population has not been examined, making it difficult to generalize previous work to such populations.

Although the cost of medical care is not within the control of individual practitioners, addressing patients' cost-related concerns is often not an unsolvable problem. Alexander and colleagues have described six practical strategies that health care providers can apply to assist their patients burdened by their out-of-pocket expenses, including switching to a less expensive but equally effective medication, stopping nonessential medicines or using them only as needed, splitting pills, using office samples, taking advantage of governmental and private pharmaceutical assistance programs, and encouraging patients to shop around for the lowest price (Alexander & Tseng, 2004). Others have described techniques for empathetic communication so that providers can assist their patients with cost-related concerns (Donley & Danis, 2011; Hardee, Platt, & Kasper, 2005). In the general medicine literature with predominately non-Hispanic white samples, the most common strategies that health care providers report using to assist their patients with cost-related concerns include switching to a generic drug, using office samples, and discontinuing nonessential medicines (Beran et al., 2007; Alexander, Casalino, & Meltzer, 2005). The use of helpful strategies to assist with cost-related concerns among individuals with asthma or vulnerable populations is not known. Additionally, no studies have examined patient perceptions of options health care providers present to assist with their out-of-pocket expenses, especially among individuals with asthma. The ability to generalize previous work to these populations is difficult given disparities in communication between clinician and patient that persist in these populations (Cooper & Roter, 2003).

Productive communication appears to ameliorate patient perceptions and concerns. More than a dozen studies show a positive and significant relationship between aspects of communication and patients' health outcomes, including recovery from emotional problems, improved physiologic and functional status, and symptom resolution (Frankel, Quill, & McDaniel, 2003). With cost of care-related communication, existing studies describe proximal outcomes associated with such discussions such as receiving samples, stopping nonessential medicines, switching from brand name to generic medicines, receiving information about financial assistance programs, and referral to support staff (Gellad et al., 2011; Beard et al., 2010; Schrag & Hanger, 2007; Wilson et al., 2007; Piette et al., 2004(a)). No studies have examined whether cost of care-related communication demonstrate associations to patients' ability to better manage their condition.

Across numerous studies, collaboration and communication between patients and clinicians prove to be highly correlated with patients' ability to self-manage their chronic condition (National Asthma Education and Prevention Program [NAEPP], 2007; Rubin, Peyrot, Siminerio, 2006). Patient-reported self-management behaviors are meaningful outcomes in health care interventions, as they are associated with critical long-term outcomes that may be difficult to measure, including functional capacity, complications, mortality, health care costs, and quality of life (Rand et al., 2012). Additionally, urgent health care utilization is an important outcome for both health systems and society. The National Asthma Education and Prevention

Program (NAEPP) has described urgent health services utilization as an important proxy measure of disease morbidity and an independent measure of asthma outcomes (NAEPP, 2007). Controlled trials with asthma patients and their health care providers have shown that over the long-term, effective communication can reduce patients’ urgent care use (Cabana et al., 2006; Clark et al., 1998). Discussion about cost of care between patients and health care providers may similarly influence self-management behaviors and asthma health outcomes, although the pathway through which this occurs has not been examined.

In an era of financial stress, understanding how communication concerning patients' perceptions of health care costs affects outcomes is important to the preservation of health status. The knowledge that communication about possible financial hardship may mitigate some of the effect observed between patient financial burden and health outcomes is important to clinical practice; the potential to expand capacity to provide simple, low-cost improvements in patient care will enable individuals with chronic conditions to take full advantage of available treatments and interventions.

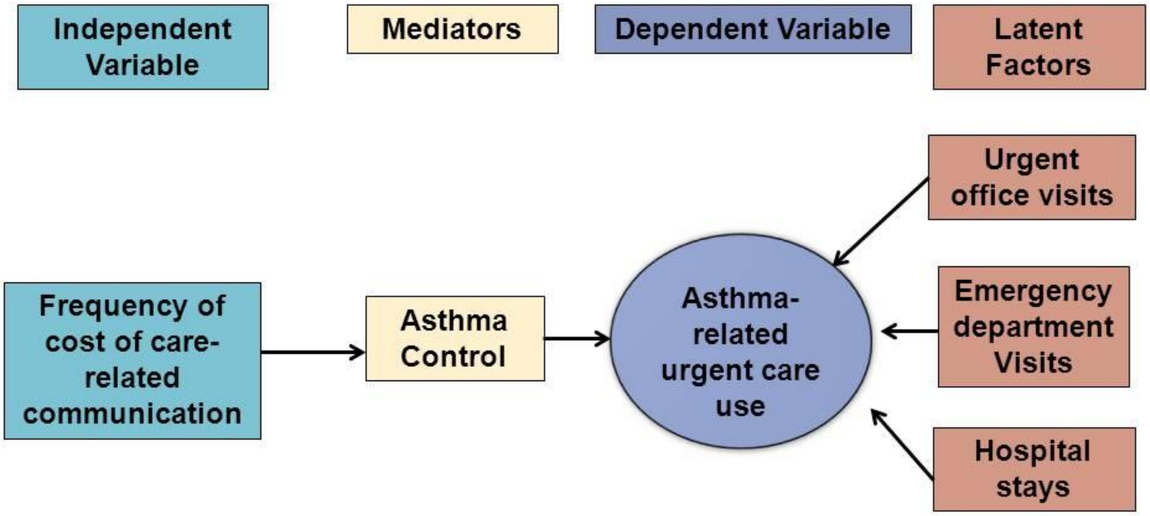
African American women comprise a unique population for examining the most difficult cases where influences of communication with a health care provider are most likely to be apparent in key outcomes. They are disproportionately affected by asthma, face the greatest challenges with self-management, have disproportionately high urgent care use for asthma, and experience worse asthma health outcomes compared to other subgroups (Centers for Disease Control and Prevention, 2011). Physicians have been shown to be less patient-centered in their communication approach with African American patients compared to non-Hispanic white patients (Cooper & Roter, 2003; Cooper-Patrick et al., 1999). Demographic disparities in general communication between patients and physicians appear to result in differential health outcomes including satisfaction with care, physiologic indicators, and compliance with medical recommendations (Cooper & Roter, 2003; Roter & Hall, 2006).

The purpose of this study was to examine the direct and indirect relationships between cost of care-related communication, self-management behaviors, and asthma outcomes among individuals with asthma and their health care providers, and options offered to women by health care providers that have proven helpful in managing asthma-related costs. Specifically, this study explored two hypotheses:

Hypothesis 1: Engaging in cost of care-related communication is positively associated with more frequent engagement in the following self-management behaviors: 1) Compliance with medicines, 2) Staying calm when experiencing asthma symptoms, 3) Avoiding triggers in the environment, 4) Removing triggers in the environment, 5) Asking the doctor questions about asthma.

Hypothesis 2: The relationship between frequency of cost of care-related communication and asthma-related urgent care use (urgent office visits, emergency department visits, and hospitalizations) will be mediated through level of asthma control (see Figure 6.1).

Figure 6.1: Conceptual structural equation model depicting outcomes of cost of care-related communication.



Methods utilized in this study are described next, followed by results, and a discussion of the findings.

Methods

The data source, sample for this study, data collection and measures, and qualitative methods are described in full in Chapter 4. New variables and methods introduced in this study are described in full here. Asthma control, which was an independent variable in the previous two chapters, is now a mediator in this study.

Measures

Frequency of cost of care-related communication

This study operationalized frequency of cost of care-related communication as how often cost of care-related communication occurs in the clinical encounter between participant and clinician. To measure frequency of cost of care-related communication, participants were asked the following question: “Do you talk with your doctor about your out-of-pocket healthcare costs when he/she recommends a test or treatment?” Response choices were measured on an ordinal scale (none of the time, a little of the time, some of the time, most of the time, all of the time). Assessment of frequency of cost of care-related communication has been measured through self-report from both the patient and clinician perspective (Benedetti et al., 2008; Shrank et al., 2006(a)), with measures demonstrating high face and content validity, and consistent findings across studies demonstrating communication occurring between 30-50% of clinical visits (Beard et al., 2010; Benedetti et al., 2008). The final measure of frequency of cost of care-related communication was used as an ordinal variable in this study.

Self-management behaviors

Self-management behaviors measured in this study include compliance with medicines, staying calm when experiencing symptoms, avoiding and removing triggers in the environment, and asking the doctor questions about asthma management. Participants were asked the following questions: ‘How many times a day do you usually miss a dose of asthma medicine?’ (1-2 times a week, 3-4 times a week, 5-6 times a week, every day, more than once a day, never), and ‘In the past 12 months, when you were having asthma symptoms, how often did you 1) ‘rest, relax, or stay calm’, 2) ‘stay away from your symptoms triggers’, 3) ‘remove symptom triggers from your environment’, 4) ‘ask your doctor specific questions about asthma management’, with response choices of all the time, fairly often, not too often, never. The final measure of each self-management behavior was used as an ordinal variable in this study.

Urgent care use

This study operationalized urgent care use as unscheduled care received for urgent asthma treatment either through unscheduled office visits, the emergency department, or hospital stays. Urgent care use was measured by asking respondents, how many times during the past 12 months they had: ‘an unscheduled visit to the doctor or clinic for urgent asthma treatment?’, ‘gone to the ED for asthma treatment?’, ‘to stay overnight at least one night in the hospital, because of your asthma?’, all assessed through open-ended responses. The final measure of each urgent care measure was used as a count variable in this study. Since urgent care experiences are usually rare events, objective and self-reports have shown relatively high concordance (Roberts, Bergstrahl, Schmidt, & Jacobsen, 1996; Cleary & Jette, 1984). Medical record data were used to validate self-report responses. Medical record data were available for emergency department visits and hospitalizations. Verification of emergency department visits and hospitalizations through medical record review was done by computation of Spearman’s rank correlation coefficient since these variables did not meet assumptions of normality (Hotellings & Pabst, 1936). The proportion of agreement was found to be statistically significant for both emergency department visits ($\rho = 0.26$, $p<0.01$) and hospitalizations ($\rho = 0.30$, $p<0.01$).

Data analysis

Intraclass correlation coefficients (ICC) were calculated in SAS 9.3 in order to assess for potential clustering of responses on asthma-related urgent care outcomes by individuals seen by the same health care provider: urgent office visits (ICC=0.76), emergency department visits (ICC=0.65), and hospitalizations (ICC=0.23), or who seek care in the same clinic: urgent office visits (ICC=0.72), emergency department visits (ICC=0.59), and hospitalizations (ICC=0.30). Design effects were calculated with average cluster size for both doctors and clinics. Design effects were not greater than 2, which typically do not result in overly exaggerated rejection proportions at the 5 percent level (Muthen & Satorra, 1995). Therefore, clustering was ignored for these variables in this analysis. This suggests a conservative analysis where standard errors may be larger and confidence intervals may be wider than would be obtained when accounting for clustering. All factors found to be significant in these analyses would remain significant if clustering was accounted for.

Missing data

Missing data were ignored, since less than 5% of missing values were present on any single variable in these data, (Kline, 2011).

Quantitative analysis

SAS 9.3 was used for all descriptive analyses. In order to normalize the distribution of skewed variables, out-of-pocket expenses, marital status, health insurance, number of individuals in the household, perceptions of financial burden, preferences and frequency of cost of care-related communication were collapsed into categories based on substantive meaning.

Frequencies were computed for each categorical variable (specialty of the care-providing clinician, asthma control, frequency of asthma symptoms, types of asthma medicines prescribed, perceptions of financial burden, marital status, employment status, number of individuals in the household, educational attainment, household income, health insurance, preferences and frequency of cost of care-related communication, self-management behaviors); means and standard deviations were computed for continuous variables (e.g., multimorbidity, total number of medications, years since asthma diagnosis, age, out-of-pocket expenses, asthma-related urgent office visits, emergency department visits, and hospitalizations).

Bivariate analyses (Student's t-test for continuous variables and contingency tables with chi-squared and Fisher's exact tests as appropriate for categorical variables) were used to examine differences in economic, demographic, and clinical characteristics between participants who reported engaging in cost of care-related discussion and participants who did not report engaging in such discussions. In bivariate analyses, frequency of cost of care-related communication was used as the outcome of interest, and analyzed as a binary variable. Dimensions of the contingency tables were as follows: 2x2 contingency tables were computed for marital status and head of household; 3x2 tables for household income, employment status, frequency of symptoms, asthma control, and asthma medications; and 4x2 tables for educational attainment, health insurance, and specialty of care.

Multivariate linear regression models were used to examine the associations between each self-management behavior as the dependent ordinal variable (compliance with medicines, staying calm when experiencing symptoms, avoiding and removing triggers in the environment, asking the doctor questions about asthma management), and frequency of cost of care-related communication as an ordinal predicator. All models were adjusted for asthma control, education, years since diagnosis, perception of financial burden, and total number of medications (variables described in previous chapters), since bivariate analysis demonstrated that all of these factors were associated with frequency of cost of care-related communication. Other work has also shown that these factors influence disease self-management behaviors (Jin, Sklar, Oh, & Chuen, 2008).

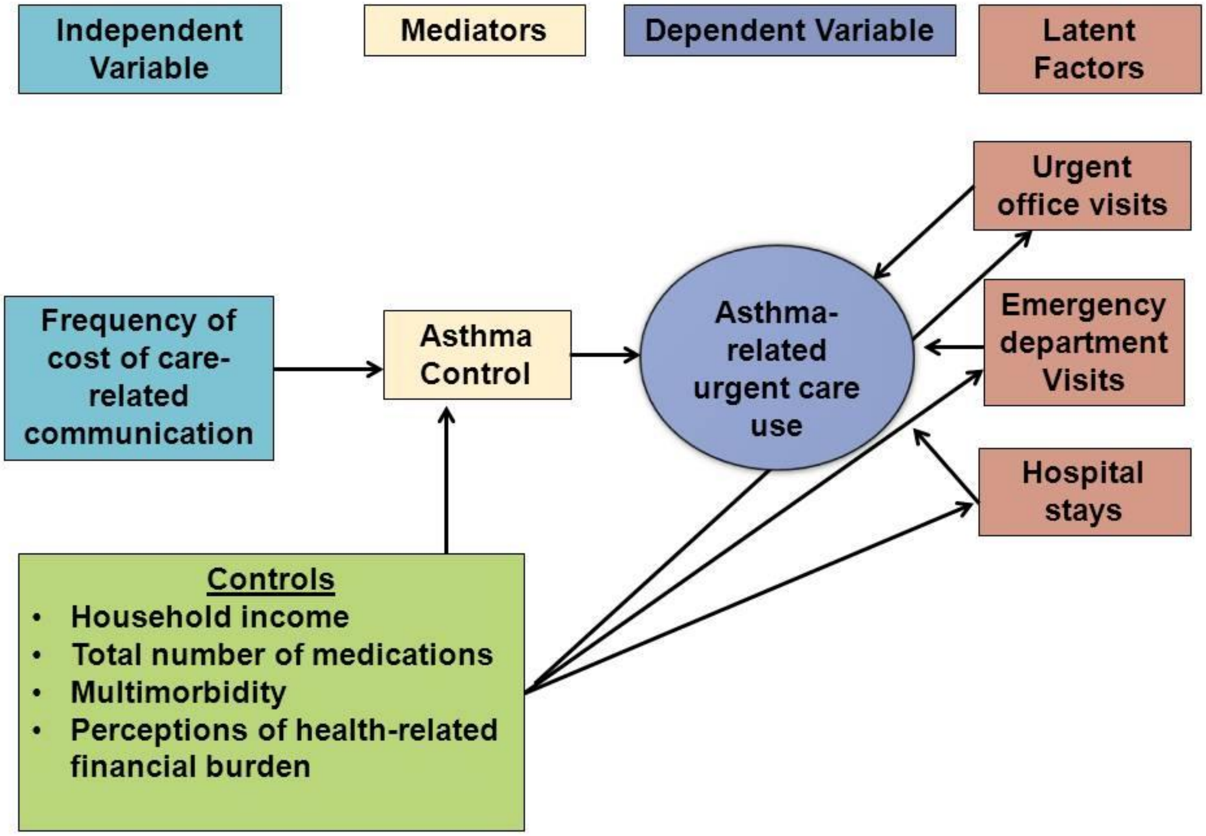
A structural equation model with observed and latent variables was used to examine indirect relationships between cost of care-related communication and participants' asthma-related urgent care use (See Figure 6.1). Structural equation modeling was used because this technique allows for the specification of a model that attempts to explain why observed and latent variables are correlated through other variables, and tests for these mediation effects through a series of regression models (Barron & Kenny, 1986; Kline, 2005). The exogenous variable in the model was frequency of cost of care-related communication. The endogenous variables in the model were asthma control (mediator), and asthma-related urgent care use (outcome) which was constructed through three observed variables (urgent office visits, emergency department visits, and hospitalizations for asthma). The estimation of the model depicted in Figure 6.1 produced unreasonable estimates, which suggests a specification error related to omitted variables (Judd & Kenny, 1981). Omitted variables in this model, variables that are associated with both the mediator (asthma control) and the outcomes (urgent office visits, emergency department visits, and hospitalizations) based on review of the literature and bivariate analysis, were deduced to be household income, total number of medications, multimorbidty, and perceptions of financial burden (Gold, Smith, Allen-Ramey, Nathan, & Sullivan, 2012; Patel et al., 2012; DeLia & Cantor, 2009; Heisler et al., 2004).

Figure 6.2 shows a revised model that was estimated, controlling for the effects of household income, total number of medications, multimorbidty, and perceptions of financial burden in the prediction of the outcome variables of interest. The exogenous variables in the model were cost of care-related communication, household income, total number of medications, multimorbidty, perceptions of financial burden, and the endogenous variables in the model were asthma control (mediator), asthma-related urgent care use (outcome).

To assess whether the sample size (n=343) provided sufficient power to detect a close fitting model (Figure 6.2), power was calculated based on power estimates from the literature for selected levels of degrees of freedom (MacCallum, Browne, & Sugawara, 1996). With a sample size of 343 and 17 degrees of freedom, power to estimate the model was 0.64. Based on another recommended assessment of sample size, the N:q rule (sample size to parameter ratio) for maximum likelihood, a ratio of 20:1 made n=343 a sufficient sample size to estimate the proposed model (Kline, 2011).

All equations were estimated simultaneously with Mplus 6.12 software. Since there were few missing data, listwise deletion was employed where cases with missing scores on any variable are excluded from the analyses. The effective sample size (only cases with complete records) was used to estimate the path models (n=324). Power to estimate the model with the effective sample size was still 0.64 as reported above. The statistical estimator used to compute the models was maximum likelihood parameter estimates with robust standard errors (MLR) and a chi-square test statistic (when applicable) robust to non-normality and non-independence of observations. This estimation method is recommended for zero-inflated dependent variables such as urgent health care use (Kline, 2011; Muthen & Muthen, 2011(a)). The MLR standard errors are computed using a sandwich estimator, which provide robust standard errors (Muthen & Muthen, 2011(a)). In all models, unstandardized estimates were computed. Mediation (significance of the indirect path) was tested using the multivariate delta method (Sobel test), as recommended by MacKinnon (MacKinnon, 2008). Correlation of parameter estimates were checked and none were found to be above 0.70 (Muthen & Muthen, 2011(a)). Since this analysis focused on a count-dependent variable, traditional goodness-of-fit statistics (e.g., RMSEA, comparative fit index [CFI], and R-square were not available to assess the fit of the model (Muthen & Muthen, 2011(b)). Alpha values of 0.05 of less were considered significant. Mediation was determined if indirect estimates had alpha values of 0.05 or less.

Figure 6.2: Analytic path model depicting outcomes of cost of care-related communication*.



*Household income, total number of medications, multimorbidity, and perceptions of financial burden were included as control variables for the prediction of four outcome variables.

Qualitative analysis

Methods are described in full in the previous chapter. Coded questions from in-depth interviews and focus groups were used to generate themes and illustrative examples to support the quantitative analysis and describe experiences with cost of care-related communication with health care providers, options that have been offered to participants that have proven helpful, asthma-related self-management and urgent care use as it relates to out-of-pocket expenses.

Comparisons and differences in themes were made between the experiences of individuals with full coverage versus partial/no insurance coverage as appropriate.

The results that follow first describe frequency of cost of care-related communication with qualitative supporting information as appropriate. Following are qualitative results of one aim of this study: helpful options offered to participants by their clinician. Next, bivariate results are presented between economic, demographic, and clinical characteristics and cost of care-related communication. Finally, the linear regression results addressing hypothesis 1 are described, following the path analytic results first describing direct relationships in the model, and then the results of the second study hypothesis. Qualitative supporting information is provided as appropriate to elaborate and provide context for the quantitative findings.

Results

Survey sample characteristics

Economic, demographic, and clinical characteristics of the sample (n=343) are described in Chapter 4.

Qualitative sample characteristics

Economic and demographic characteristics of focus groups (n=14) and in-depth interview participants (n=25) are described in Chapter 4.

Frequency of cost of care-related communication and initiation of discussion

Thirty-nine percent (n=134) reported that they discuss the cost of their care with their health care provider, and within this group, 75% (n=100) initiate the discussion.

In both the full and partial/no insurance focus groups, many participants mentioned that they initiate the discussion of cost more often compared to whether their clinician brought it up. Some participants in the partial/no insurance group mentioned that their physicians ask them.

One woman in this group mentioned that she perceived clinicians are aware of the patients' burden:

> "And a lot of doctors will ask because they know that the cost of the, um, medication is so high. They will ask. I – my doctor – I've had doctors ask, you know, "are you insured or do you have, um, medication coverage?" And if you don't, they'll provide, um, handouts, or you can get free medication."

In both focus groups, participants most often identified their physician and social workers as most helpful in assisting with cost-related concerns. Other members of the care team participants identified as supportive in cost and insurance related situations were nurses and pharmacists.

Negotiation

A theme in the partial/no insurance group emerged around the importance of negotiating cost with a health care provider. Some participants voiced that they did not realize such options were available to them in the context of the clinical encounter. One woman with private insurance was unaware that she could negotiate:

> "So, it's really important, and I never, ever thought that it was an option to negotiate. Ever. My husband does that all the time, and I wonder how he can think to do it. He doesn't pay standard for anything, but I'm not, I, I, I'm like, "OK, the rule is I have to pay what they say." That's been my mindset."

Experienced participants noted their confidence in engaging in negotiation with their provider around cost and educated others in the group about how to do so. Self-efficacy with such discussions was high among participants as evident by such comments:

> "I ain't ashamed. "Is it covered," "how much is the co-pay," "what do I have to pay out of pocket?" Uh-uh. I have no problem."

Some participants noted their experiences and success in engaging in negotiation with their provider. One woman noted that she relies on negotiation when she has gaps in her insurance coverage:

> "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."

Options offered by health care providers that are helpful for cost of care-related challenges

From focus groups, participants described several options offered by clinicians in order to manage the high out-of-pocket costs associated with their asthma treatment. From both focus groups, participants revealed that these options primarily focused on medicines. Participants asserted that their physicians will write prescriptions for as many of their medications as possible, including vitamins and over-the-counter medicines, so that their health insurance covers those costs. Several participants noted that when they expressed concerns about cost, their providers offered them an affordable alternative option. One woman in the partial/no insurance group noted that her provider was accommodating to her cost 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."

Some participants in the partial/no insurance group mentioned that their physicians offer them options to make payments on their co-pay or medical bills or gave them options of renting medical equipment (such as the nebulizer). In both focus groups, samples were most often mentioned as a helpful option that both physicians and pharmacists offered to their patients. One woman in the partial/no insurance group mentioned that when she asked, she was able to count on receiving medicine from her provider:

> "um, many years ago when we were really struggling. I didn't have any money even for my children for their medicine, and my doctor just gave me samples. He gave me about six months worth of samples. He said, "just come back when you need more."

One woman in the full insurance group mentioned that even pharmacies carry samples for patients in need:

> "The pharmacy will give you – like, if they know you on a certain medication, and you don't have no insurance for something for a minute, they'll give you an inhaler or something. My pharmacy real good. He love me. He just give me, "what you need"."

Bivariate relationships between economic and demographic factors and cost of care-related communication

Table 6.1 describes economic and demographic characteristics of participants who do and do not report discussing the cost of their care with their health care provider. Demographic factors significantly associated with cost of care-related communication were found for higher age (t=-3.46, p<0.001), and part-time or no employment ($X^2(2) = 7.86$; p<0.01). Perception of financial burden ($X^2(1) = 28.01$; p<0.001), and preference for communication ($X^2(1) = 67.00$; p<0.001) were also associated with actually engaging in such discussions with their clinician. No associations were observed with economic factors.

Bivariate relationships between clinical characteristics and cost of care-related communication

Table 6.2 describes clinical characteristics of participants who do and do not report discussing the cost of their care with their health care provider. Clinical factors associated with cost of care-related communication were found for more years since asthma diagnosis (t=-2.47; p<0.01), worse asthma control ($X^2(2) = 10.45$; p<0.01), more medications (t=-3.62; p<0.001) and more chronic conditions (t=-4.15; p<0.001).

Cost of care-related communication and asthma self-management behaviors.

The results that follow address whether self-management behaviors are associated with cost of care-related communication. Table 6.3 shows adjusted multivariate linear regression models of cost of care-related communication with a health care provider and relationships to asthma self-management behaviors. The results did not support hypothesis 1. No significant associations were found between each of the five self-management behaviors and cost of care-related communication when adjusted for asthma control, education, years since diagnosis, perception of financial burden, and total number of medications.

Table 6.1: Economic and demographic characteristics of participants who do and do not report discussing the cost of their asthma care with their health care provider.

Variable	**Total sample (N=343)**	**Cost-related discussion with provider (N=134)**	**No cost-related discussion with provider (N=208)**	**t or X^2**
Age (mean, SD)	43.11 (14.82)	46.52 (14.31)	40.92 (14.79)	**t=-3.46****
Marital status (% Married)	29% (100)	30% (40)	29% (59)	X^2 (1)=0.07, *NS*
Head of household (% yes)	67% (230)	65% (87)	69% (143)	X^2 (2)=2.69, *NS*
Number of individuals in the household				X^2 (3)=0.77, *NS*
1	38% (132)	38% (51)	39% (81)	
2	27% (92)	29% (39)	25% (52)	
3	15% (51)	14% (19)	15% (32)	
4 and more	20% (68)	19% (25)	21% (43)	
Educational attainment				X^2 (2)=2.68, *NS*
High school /GED or less	21% (70)	19% (25)	22% (45)	
Some college, associate's degree, or vocational school	47% (162)	44% (59)	49% (103)	
Employment status				**X^2 (2)=7.86****
Part-time	26% (87)	31% (40)	23% (46)	
Full-time	39% (131)	30% (39)	45% (92)	
No employment	35% (114)	39% (50)	32% (64)	
Household income				X^2 (2)=3.49, *NS*
<\$20,000	42% (137)	44% (57)	41% (80)	
\$20,001 - \$40,000	24% (79)	27% (35)	22% (44)	
\$40,001 - \$60,000	18% (57)	17% (22)	18% (35)	
>\$60,001	16% (52)	12% (15)	19% (37)	

Table 6.1: Continued

Variable	Total sample (N=343)	Cost-related discussion with provider (N=134)	No cost-related discussion with provider (N=208)	t or X^2
Health insurance				[a]X^2 (3)=5.75, *NS*
No insurance	2% (6)	2% (3)	1% (2)	
Private	45% (153)	40% (54)	48% (99)	
Medicare only	2% (8)	4% (5)	1% (3)	
Medicare + supplemental coverage	18% (62)	22% (29)	16% (33)	
Medicaid only	27% (92)	23% (31)	29% (61)	
Other government	6% (22)	9% (12)	5% (10)	
				X^2 (1)=0.45, *NS*
[b]Full health insurance	51% (176)	54% (72)	50% (104)	
[c]Partial health insurance	49% (167)	46% (62)	50% (104)	
Out-of-pocket expenses (mean, SD)	\$163.27 (308.27)	\$191.35 (292.96)	\$146.02 (317.83)	t=-1.35, *NS*
(Range)	\$0-\$2,840	\$0-\$2,040	\$0-\$2,840	
Perception of financial burden (% yes)	53% (180)	70% (94)	41% (85)	**X^2 (1)=28.01*****
Preference for cost of care-related communication (% yes)	73% (251)	98% (131)	58% (120)	**X^2 (1)=67.00*****
Initiate cost-related discussion				
Physician		20% (27)		
Patient		75% (100)		
No one		5% (6)		

Student's t-test and chi-square tests were performed on demographic variables of interest to identify differences between the groups. NS= not significant. Level of significance reported as (p-value): *p<.05, **p<.01, ***p<.001.

a. Due to low cell count, chi-square test is based on the associations between private, Medicare + supplemental coverage, and Medicaid only.
b. Partial insurance= private, no insurance, Medicare only.
c. Full insurance= Medicaid, Medicare and supplemental coverage, other government insurance.

Table 6.2: Clinical characteristics of participants who do and do not report discussing the cost of their asthma care with their health care provider.

Variable	Total sample N=343	Cost-related discussion with provider (N= 134)	No cost-related discussion with provider (N=208)	P-value, t or X^2
Specialty of care				$^{a}X^2$ (2)=1.73, *NS*
Primary care and specialist	33% (113)	37% (50)	30% (63)	
Primary care only	59% (200)	56% (75)	60% (125)	
Specialist only	6% (21)	5% (7)	7% (14)	
No doctor	2% (8)	2% (2)	3% (5)	
Years since asthma diagnosis (Mean, (SD))	18.01 (14.77)	20.62 (16.71)	16.32 (13.13)	**t=-2.47****
Frequency of symptoms				X^2 (2)=2.98, *NS*
<2 days per week	61% (210)	56% (75)	64% (134)	
≥ 3 days per week	28% (95)	33% (44)	25% (51)	
Throughout the day	11% (38)	11% (15)	11% (23)	
Asthma control				**X^2 (2)=10.45****
Well controlled	30% (101)	23% (31)	34% (70)	
Not well controlled	31% (107)	27% (36)	34% (70)	
Very poorly controlled	39% (135)	50% (67)	32% (68)	
Asthma medications				$^{b}X^2$ (3)=1.83, *NS*
Controller and rescue	70% (238)	70% (93)	71% (145)	
Controller only	4% (13)	5% (7)	3% (6)	
Rescue only	19% (64)	16% (22)	20% (41)	
Allergy only	1% (1)	1% (1)	0% (0)	
Allergy and rescue only	3% (11)	4% (5)	3% (6)	
Leukotriene modifier and rescue	2% (8)	4% (5)	2% (4)	
Leukotriene modifier only	1% (1)	0% (0)	1% (1)	
Total number of medications (Mean, SD)	5.32 (2.88)	6.03 (2.91)	4.88 (2.78)	**t=3.62*****
Total number of other chronic conditions (Mean, (SD))	3.65 (2.57)	4.36 (2.65)	3.20 (2.42)	**t=-4.15*****
Asthma-related Emergency department visits (Mean, SD)	0.97 (1.69)	1.16 (2.00)	0.85 (1.46)	t=-1.65, *NS*

Table 6.2: Continued

Variable	**Total sample N=343**	**Cost-related discussion with provider (N= 134)**	**No cost-related discussion with provider (N=208)**	**P-value, t or X^2**
Asthma-related Hospitalizations (Mean, SD)	0.29 (0.80)	0.34 (1.00)	0.26 (0.66)	t=-0.85, *NS*
Asthma-related urgent office visits (Mean, SD)	1.70 (2.30)	1.97 (2.77)	1.53 (1.93)	t=-1.72, *NS*

Chi-square tests were performed on clinical variables of interest to identify differences between the groups. NS= not significant. Level of significance reported as (p-value): *p<.05, **p<.01, ***p<.001.

a. Due to low cell count, chi-square test is based on the associations between primary care and specialist, primary care only, and specialist only.
b. Due to low cell count, chi-square test is based on the associations controller and rescue, controller only, rescue only, and allergy and rescue only.

Qualitative examinations suggest that self-management behaviors may be affected by out-of-pocket expenses and the provision of health insurance. In focus groups, the majority of participants expressed that their out-of-pocket expenses do affect their ability to manage their asthma. Two common behaviors participants reported included forgoing medicines or managing their asthma through the emergency room. These behaviors were described in the context of not having insurance coverage. One woman in the full insurance group mentioned foregoing her medicine when she was uninsured:

> “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.”

Another woman in the full insurance group described the emergency department as her source of getting her asthma under control when not having insurance.

> “when you don’t have insurance, the way you manage asthma is through the emergency room. So, you will literally wait until you have- until you have to go --an attack, and the only way you can get medication is to go to the emergency room.”

Table 6.3: Adjusted multivariate linear regression models of cost of care-related discussion with the clinician predicting asthma self-management behaviors.

Variable	Total Sample (n=343)	Cost-related discussion with physician (n=134)	No cost-related discussion with physician (n=208)	[a]Estimate (SE)
Compliance with medicines				-0.039 (0.06)
Never	9% (31)	7% (10)	10% (21)	
Fairly often	29% (99)	30% (40)	28% (58)	
All the time	62% (212)	63% (84)	62% (128)	
Staying calm when experiencing asthma symptoms				0.009 (0.06)
Never	14% (47)	13% (18)	14% (29)	
Fairly often	47% (160)	48% (64)	46% (96)	
All the time	39% (135)	39% (52)	40% (82)	
Avoiding triggers in the environment				-0.10 (0.05)
Never	14% (48)	11% (15)	16% (33)	
Fairly often	56% (193)	64% (85)	51% (107)	
All the time	30% (102)	25% (34)	33% (68)	
Removing triggers in the environment				-0.06 (0.05)
Never	24% (83)	22% (29)	26% (53)	
Fairly often	44% (152)	49% (66)	41% (86)	
All the time	32% (108)	29% (39)	33% (69)	
Asking the doctor questions about asthma				0.01 (0.05)
Never	52% (178)	44% (59)	57% (118)	
Fairly often	25% (87)	29% (39)	23% (48)	
All the time	23% (77)	27% (36)	20% (41)	

NS= not significant. Level of significance reported as (p-value): *p<.05, **p<.01, ***p<.001.

a. Adjusted multivariate models of cost-related discussion with the physician predicting asthma self-management behaviors. Models adjusted for, asthma control, education, years since diagnosis, perception of financial burden, total number of medications.

One woman in the full insurance group discussed how rationing affected her management and described asthma as a condition where weighing decisions between purchasing high cost medicines or waiting becomes difficult due to the severity of illness exacerbation:

> “That’s the amazing, um, other side of it, with asthma. Unlike any other chronic illness, the alternative is not breathing. So, you don’t have a choice. You will sit and contemplate, “you know, what I need to get this medication and this inhaler, but I can go about 10 more days without an inhaler, and I’ll be good. If I’m not, I’ll just go to the emergency room. Which really, you shouldn’t do that, so you really contemplate it so you don’t have to pay $400 for an inhaler. And it does make you anxious and full of anxiety, but you get over it after a while.”

Structural equation model results

A structural equation model that allowed for the simultaneous estimation of multiple equations was computed so that associations between multiple predictor and an outcome variable composed of latent factors could be assessed in the same model. The results address the second aim of this study to explore indirect relationships between cost of care-related communication and asthma-related urgent care use. The results that follow first describe the direct relationships in the model and then the study hypothesis: level of asthma control will mediate the relationship between cost of care-related communication and asthma-related urgent care use.

Direct effects in model of cost of care-related communication on health outcomes

Table 6.4 shows direct effects in the model of cost of care-related communication on health outcomes, specifically asthma control and asthma-related urgent care use. The results that follow report unstandardized estimates. In the model, no direct relationships were observed between cost of care-related communication and asthma control. Worse asthma control was found to be directly associated with more asthma-related urgent care use, when adjusted for cost of care-related communication, household income, total number of medications, multimorbidty, and perceptions of health-related financial burden (β=0.329 (SE=0.078), p<0.001).

Indirect effects in the model of cost of care-related communication on health outcomes

Table 6.5 shows indirect effects in the analytic model of cost of care-related communication on health outcomes, specifically asthma control and asthma-related urgent care use. Hypothesis 2 was not supported. No indirect, significant relationship was found for cost of care-related communication and asthma-related urgent care use, when adjusted for household income, total number of medications, multimorbidty, and perceptions of financial burden (β=0.083 (SE=0.05), p=0.126).

Qualitative investigations revealed differences between individuals with full versus partial/no insurance coverage in terms of their preferences for asthma-related urgent care. Participants in the partial/no insurance focus group described using urgent care facilities more when seeking emergency services related to asthma due to their low cost, efficiency, and greater availability. One woman with private insurance described the efficiency she experienced with urgent care facilities:

> “And I’m glad they’re popping up all over. They’re becoming more plentiful. And they get you in. They get you in, they get you out. For me, I have to just pay my regular office co-pay.”

Table 6.4: Direct effects in the structural equation model of cost of care-related communication on urgent care use outcomes.

	Asthma control	**Urgent office visits**	**Emergency department visits**	**Hospitalizations**
PREDICTORS	[a]Estimate (SE)	[a]Estimate (SE)	[a]Estimate (SE)	[a]Estimate (SE)
Frequency of cost of care-related communication	0.254 (0.155)			
Asthma control		0.291*** (0.078)	0.380*** (0.118)	0.521** (0.175)
Household income	-0.334*** (0.104)	-0.017 (0.070)	-0.128 (0.089)	0.011 (0.138)
Total number of medications	0.202** (0.070)	0.098*** (0.030)	0.067* (0.035)	0.151** (0.059)
Multimorbidity	-0.107 (0.077)	-0.031 (0.03)	-0.032 (0.051)	-0.055 (0.066)
Perceptions of financial burden	0.217 (0.15)	0.226* (0.112)	0.116 (0.151)	0.286 (0.251)

$P<0.05$*, $P<0.01$**, $P<0.001$***; SE= standard error.

a. Estimate is unstandardized.

Table 6.5: Indirect effects in the structural equation model of cost of care-related communication on health outcomes.

Path	**Unstandardized Estimate (SE)**
Frequency of cost of care-related communication → Asthma control → Urgent office visits	0.073 (0.04)
Frequency of cost of care-related communication → Asthma control → Emergency department visits	0.096 (0.06)
Frequency of cost of care-related communication → Asthma control → Hospitalizations	0.132 (0.09)

P<0.05*, P<0.01**, P<0.001***

On the other hand, participants in the full insurance focus group valued the emergency room relative to urgent care, due to comprehensive services available to manage and treat asthma exacerbations. One woman described differences in the quality of asthma care between urgent care and emergency room facilities:

> "Because their – urgent care really can't address—the asthmatics. Yeah. They'll send you to the emergency room. The emergency room is the best place. -you need to go to the emergency room. Yeah, because when I've gone to urgent care, that's exactly what they said. You need to go to the emergency room."

Finally, participants noted other reasons why they may use acute care. It was most commonly noted that regardless of cost, some participants described urgent care use as inevitable due to their triggers. One woman with private insurance anticipates a hospital stay every year:

> "And every year, I end up in the hospital for asthma, a change in the weather. I don't care, get upset. I'd be in the hospital every year."

Another woman in the full insurance group attributed her asthma-related urgent care use to ineffective medicines.

> “oh, and going to the emergency room every damn three months or so--when the medication fails. I went to the emergency, like last summer, three, four times.”

Discussion

The purpose of this study was to examine the pathway through which cost of care-related communication may influence asthma outcomes within a high-risk population with asthma. This is the first study to examine these relationships in an adult population with a chronic disease. Less than half the sample reported discussing the cost of their asthma care with their health care provider, although more than three quarters of participants reported preferences for such discussions. Bivariate analyses showed that more individuals who reported no or part-time employment, older age, longer duration of time since asthma diagnosis, poor asthma control, more medications, perceptions of financial burden, and a preference for communication, also reported actual discussion of cost of care with their provider. These findings reinforce previous work that has shown demographic differences among individuals who report cost of care-related communication with their provider (Beard et al., 2010; Piette et al., 2004(a); Alexander et al., 2003).

This study went a step further from previous work to examine whether the actual communication of cost between clinician and patient influences asthma self-management behaviors, and indirect relationships to asthma-related urgent care use via asthma control. No support was found in these data. There may be several reasons why an effect was not seen. Secondary data analysis limited data to what was already available. The measure of actual communication of cost asked participants how often they talk to their doctor about their out-of-pocket costs. The measure did not capture the content of the communication or quality, nor was any quantitative data available on this in the data sources. Relationships to self-management behavior and urgent care outcomes may be dependent on the quality of the communication and what immediately results from the dialogue. For example, what did the clinician actually do or not do to assist the patient with their cost concerns in order to better self-manage. A better understanding of what entails productive communication around cost between clinician and patient is certainly needed.

It may also be possible that the specific content of cost of care-related communication between clinician and patient exhibits different pathways to self-management behaviors and health outcomes. For example, a cost-related challenge around the cost of asthma medicines may influence health outcomes through obtaining medicines and then taking them, whereas a cost-related challenge around the cost of transportation or lost work time to receive routine care may exhibit different pathways to health outcomes. The qualitative findings suggested that some participants were receiving supportive resources from their health care provider to assist with cost-related challenges in managing their asthma. Cost of care-related communication and self-management behaviors may not be directly related, but rather imply that a cost-sensitive treatment plan or an immediate, helpful outcome from the clinician-patient discussion may mediate this relationship. Data regarding specific outcomes from cost-related discussion were not available in the data source; this precluded a more thorough examination of the effect of cost of care-related communication on self-management behaviors. Alternatively, for cost-related challenges, there may be other factors beyond communication that influence self-management behavior. The sequence of events that transpire to affect patients’ health after clinician and patient communicate patients’ cost-related concerns requires more conceptual clarity and data to analyze such associations. These limitations present opportunities for future research. Introducing more proximate mediators may better help understand these processes.

The conceptual relationships between cost of care-related communication and asthma-related urgent care may also be more complex than this study revealed. Qualitative findings suggested that cost impacts some participants' asthma self-management, and patients' reasons for using urgent care for asthma are varied and complex. There may be alternative models. This study hypothesized that communication may lead to decreased urgent care use. Alternatively, it may be that urgent care use, associated with high out-of-pocket expenses and often indicative of poor quality of care or access-related challenges (Hearld & Alexander, 2012; Institute of Medicine, 2009(b)), precipitates perceptions of financial burden and subsequent need for cost of care-related communication with a health care provider. Some data support this assumption. A large fraction of bankruptcies in the U.S. come from Americans without health insurance who run up five to six-figure hospital bills, sometimes during one emergency or episode requiring intensive hospital care (Cohn, 2008). The study hypothesized the causal effects to be unidirectional but qualitative examples suggest that cost of care-related communication and health outcomes may exhibit non-recursive relationships. The need for conceptual clarity and refined tools to capture these processes may support these mixed findings. However, this study adds to the literature by suggesting that unidirectional methodological and analytical approaches may limit our understanding of the complex relationships between cost of care-related communication and health outcomes. This may lead to inadequate conclusions about patient behavior and the utility of cost of care-related discussions on improving patients' health.

We also asked participants how often they talk to their doctor about cost. It may be that communication may not be coming from the right person in the care team or patients may be discussing their cost concerns with another care provider. Qualitative investigations revealed that participants identified physicians, social workers, nurses, and pharmacists to be helpful individuals among their care team in assisting with their cost-related concerns. It may be the act of triaging to someone who is better equipped to address financial concerns demonstrates relationships to outcomes. Figuring out the right person and processes for addressing these concerns is an opportunity for further research.

Participants report initiating the dialogue around cost concerns more often, suggesting that providers are either unaware of the patient need for such communication, or they face barriers in having such conversations. Eliciting clinician perspectives is imperative in further understanding and potentially promoting cost of care-related communication as a potential intervention for mitigating perception of financial burden. The data were limited in understanding if clinicians were receptive to patient initiation of cost-related discussions even if they did not frequently initiate the conversation. Since clinicians provide therapeutic and disease management recommendation, a better understanding of initiation and receptivity of cost concerns between clinician and patient appears necessary in order to ensure that patients are equipped clinically to manage their condition. Whether or not the resolution of cost-concerns appears necessary during the time spent with the clinician requires further investigation.

Among patients who reported no cost of care-related discussion with their health care provider, half reported perceptions of financial burden and a preference for such discussions. These findings suggest that half of patients who do not discuss the cost of care with their health care provider want to have these discussions but may face barriers in initiating and engaging in them. The social distance observed between clinician and patient may have precluded cost of care-related communication for some participants in this sample. Other work suggests that levels of verbal activity between clinicians and patients of disadvantaged social groups are typically low (Waitzkin, 1985; Pendleton & Bochner, 1980; Bain, 1979). Alternatively, individuals with economic resources or whose situations suggest economic security may perceive or have actually experienced their perceptions of burden not taken seriously by their provider, since resources typically increase expectations to pay out-of-pocket. Some participants in this sample may not have felt comfortable being forthcoming about their cost-related concerns. Furthermore, qualitative investigations revealed that many are unaware that a health care provider can be helpful in this area. Nonetheless, these findings suggest that for many patients, their communication preferences are not being met. Given that communication is central to how therapeutic goals are achieved, these findings provide further support that clinician inquiry about patients' perceptions of their ability to bear the costs associated with treatment recommendations becomes imperative in providing patient-centered care.

Obtaining free samples from their health care provider was the most common helpful option mentioned by participants in mitigating their cost-related concerns. However, the process of obtaining samples may further necessitate communication between clinician and patient due to increased regulation on pharmaceutical and health practitioner relationships, which has decreased the availability of such options at the point of care (Rothman & Chimonas, 2010; Institute of Medicine, 2009; Brennan et al., 2006). Following a call to action between industry and health care practitioners (Institute of Medicine, 2009(a); Brennan et al., 2006), several major academic medical centers (including the University of Pennsylvania, University of Pittsburgh, Stanford University, and the University of Michigan) have instituted strict policies around the provision of samples. Although the provision of free samples of prescription drugs or devices provides invaluable assistance to some patients at the point of care, regulatory concerns (including potential safety risks for patients, and encouragement of prescribing new, high cost medications whose safety and efficacy may not be different from existing treatments) have necessitated alternative methods of preserving the benefit of samples outside of direct interaction between pharmaceutical representatives and physicians (Brennan et al., 2006). There is no uniformity among leading institutions' policies for drug samples; some academic medical centers use a system where physicians can log into an electronic system and order them, while others offer vouchers to their patients, or house samples in the pharmacy if they are on formulary (Rothman & Chimonas, 2010). Regardless of the method, medication samples may not be available at the point of care for many patients with cost-related concerns. The existence of alternative methods for obtaining samples may necessitate a discussion between patient and clinician.

Observations during focus group data collection in this study showed that participants were educating each other on how to access community resources for cost of care-related concerns, and how to communicate and negotiate cost with their provider. This observation has implications for the development of health education interventions for individuals particularly vulnerable to perceptions of financial burden. In patients with chronic illnesses, group interventions have become popular as an adjunct to medical treatment, and prove to be both cost-effective and effective for individuals in receiving information and behavioral skills training (van der Ven, 2003). They may be similarly effective in the context of addressing perceptions of financial burden by providing a venue to learn about navigating complex systems for obtaining low-cost care options from experienced peers, and negotiating in a clinician-patient context that is historically hierarchical and patriarchal. Peer-led group interventions may be especially effective for individuals who face barriers in accessing information due to inadequate health literacy or lack access to technology.

There are several limitations in this study that should be noted in considering its implications. The concurrent mixed methods approach in this study revealed limitations in terms of using qualitative data to clarify the quantitative approaches. Given the potential conceptual and data limitations that may explain the quantitative findings concerning self-management behaviors and asthma-related urgent care use, the opportunity to use qualitative data to inform the measures and specify the pathways in the analytic models may provide a more informed assessment of the relationships of interest.

SEM procedures require measures to have strong psychometric properties to ensure stable statistical estimation (Kline, 2011). Existing tools to measure cost of care-related communication and self-management behaviors may be conceptually inadequate. Psychometric properties of existing measures of cost of care-related communication are unknown and thus cannot capture the content, quality, or duration of such discussions. Although theoretically meaningful constructs can be developed by using latent variables (which improve the measurement quality of data and adjust for random measurement error), latent factors that would comprise cost of care-related communication have not been examined and present opportunities for further exploration.

The measures used to assess self-management behaviors may not have captured all of the behaviors that participants may engage in to manage their asthma. Few validated measures exist to measure the extent to which individuals use self-management behaviors, and direct observation (e.g., observing administration technique using metered-dose inhalers, measuring air nicotine and allergen levels) requires more resources to measure and may in themselves influence behavior (Rand et al., 2012). Self-report of medication adherence from the quantitative survey data may overestimate adherence, as this construct tends to be over reported when elicited through self-report (Stone et al., 1999). 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 (Rand et al., 2012), the qualitative findings from Chapter four suggest that these measures may not capture true adherence for all individuals with asthma. Participants report stockpiling medicines or sharing medicines with family members as a result of cost-related concerns or challenges, or anticipating these challenges in the future. Existing measures of medication adherence may require further exploration that take into account "survival"-related behaviors.

Other factors may have a stronger influence on patients' self-management than the discussion of cost. The lack of methods available to assess fit in models with count outcome variables precluded the estimation of the amount of variance explained by cost of care-related communication in the models. It is also possible that an outcome of a cost-related discussion is a better predictor of self-management than the discussion itself. Although the qualitative findings in this study suggested that some participants in this sample have been offered helpful options by their health care providers, the lack of quantitative data available precluded quantifying how often this occurs or from whom in the care team these options come from.

The ability to note subtle distinctions in variables collapsed via Likert response scales or response distribution may have been lost. To address this, collapsed variables were checked to see if they achieved similar results when collapsed differently around cut-points. Results demonstrated similar results in the same direction.

Power based on the sample size and model degrees of freedom (i.e. close-fit hypothesis) suggested that it was low for this study (MacCallum, Browne, & Sugawara, 1996). Low power using a close-fit hypothesis often leads to not rejecting a model that should be rejected, that is, favoring a researcher’s model. According the Kline, precision to estimate the model in this study was evident based on the sample size and number of parameters estimated (Kline, 2011). However, the additional parameters estimated in the revised model required a larger sample size than what was available based on the sample size to parameter rule. What low power means for this study is unclear because there was no ability to assess model fit. If such statistics were available, they would be difficult to interpret because the power was low.

The data were cross-sectional. Therefore, the true direction of association between some variables may not be easily discerned. Longitudinal data would provide more opportunities to examine reciprocal or non-recursive relationships between cost of care-related communication, behavior, and health outcomes.

Since this study utilized secondary data for the item-specific survey and in-depth interview data, limitations were that items may have been measured differently than anticipated, limited to what already exists, or may be incomplete. With the qualitative data collection obtained through focus groups, social desirability and the group format may have precluded individuals from sharing their true experiences with asthma self-management and urgent care use as related to out-of-pocket expenses.

Finally, the study sample comprised African American women receiving care in Southeast Michigan. As a result, findings may not be generalizable to all women or all adults with asthma or those receiving care in other regions. Because inclusion criteria for the study required participants to receive care for their asthma, the number of individuals who report not having a health care provider for their asthma may be greater than reported here.

Lastly, this study did not elicit the perspective of the clinician in clinician-patient discussion around the cost of care, and their lack of initiation of such conversations. This may limit a full understanding for intervention development and important clinician or health system factors that may influence the relationships between cost of care-related discussion, patient self-management, and health outcomes.

Despite these limitations, this study has strengths. The qualitative data suggested some potential value in the discussion of cost of care between clinician and patient in increasing individuals' abilities to self-manage their condition. However, this study revealed that for a large proportion of patients, their communication preferences around cost are not being met, and this discussion is often patient-initiated when it does occur.

Implications

Given that communication preferences for patients around cost are not being fully met, the findings from this study have a number of implications for research, behavioral interventions, and clinical practice.

Clinical Practice

Health care reform through the Patient Protection and Affordable Care Act (PPACA) is migrating towards aligning provider incentives with quality and better patient outcomes, therefore engaging patients as a full partner in their care will become critical for providers in the care they deliver. With the PPACA, people will have more options in terms of their care seeking. My findings supported that cost of care-related communication is desired. This may be linked to satisfaction, which is an important outcome to clinicians, payers, and the viability of health systems.

There is good reason to increase cost of care-related communication in an efficient way now; even if the available evidence does not show that it affects self-management or health care use. First, patient preferences are not being fully met, therefore engaging patients in conversations around factors that may impact their ability to manage their health becomes imperative in providing patient-centered care. Second, patients need to communicate with health care providers in order to access affordable options (e.g. free samples, verification to access community assistance programs). Third, such communication could potentially include behavior change, particularly with providers, to reduce overall health care costs and improve patient health. Provider-induced demand (which is one part of a larger issue of supply-induced demand, in which the availability of more resources influences utilization), where health care providers encourage patients to consume services that patients would not have otherwise chosen had they been fully informed, is particularly apparent in the management of chronic diseases (Dartmouth Atlas of Healthcare, 2007). This behavior has led to large regional variation in health care spending and contributes to wasteful healthcare expenditures without evidence of improving patient health (Dartmouth Atlas of Healthcare, 2008). Subsequent increases in the already catastrophic U.S. healthcare deficit raises and shifts healthcare costs to consumers. Engaging in cost-related discussions with patients may potentially self-regulate health care providers to provide appropriate and cost-efficient care.

Some patients recognize that they can negotiate the cost of their healthcare, therefore clinicians may need to be prepared to engage in such conversations with their patients. Some patients are interested in low cost options, therefore clinicians may also prepare their practice settings to have information on such options readily available. This includes information on accessing samples or community assistance programs.

Research

In order to promote and widely implement the discussion of cost between clinician and patient as an important health care delivery solution, development of the evidence-base that can speak to the effectiveness of such discussions is necessary. Such an evidence-base base will need to clarify the relationships between cost-related discussions and meaningful patient health outcomes such as improved disease control, decreased urgent care use, patient satisfaction, and patients' quality of life. More evidence is needed in understanding what entails quality and sufficient communication about cost between clinician and patient and how care teams can efficiently manage such concerns given varied expertise around the financial aspects of disease management. For some clinicians and practice settings, incorporating such discussions as part of routine care may compete with the inertia of previous practice; therefore, strengthening the evidence-base will be imperative to changing clinical practice. Additionally, a stronger evidence-base will inform the development of clinician interventions that foster seamless incorporation of cost of care-related discussions into practice.

In strengthening the evidence-base of the utility of cost of care-related communication, several other implications for research are evident. Re-specifying and testing alternative models is a logical first step. Mixed methods approaches are imperative for understanding complex relationships between cost of care-related communication and patient health outcomes. Future studies may consider sequential mixed methods study designs whereby qualitative data inform conceptual linkages, model specification, and the development of quantitative measures, data collection and analysis before hypothesis testing. Future research may also continue to utilize multiple formats of qualitative data collection, given limitations that social desirability poses in group formats. Future studies may also consider using latent variables to construct health outcomes in order to aggregate similar observed variables to represent a single underlying concept.

Although the development of fit statistics is an active research area in SEM, more work towards developing fit statistics for count outcomes is imperative in order to aid researchers in discerning relationships between cost of care-related communication and meaningful health outcomes that are rare events. Although fit statistics in general in SEM pose several limitations (Kline, 2011), at the very least, they provide a cue for diagnostic investigation that may be helpful early in analytic stages because they indicate discrepancies between the model and data.

Since clinicians play a critical role in patients' treatment trajectory, further investigations of clinician perspectives in engaging in cost of care-related communication with their patients may strengthen the evidence-base for intervention.

Ensuring sufficient power by utilizing larger samples would increase the precision to estimate hypothesized effects. Exploring the relationships between cost of care-related communication and health outcomes in heterogeneous samples where findings can be more broadly generalized is also recommended. Lastly, chronic diseases may vary in terms of pathways between cost of care-related communication and health outcomes. Meaningful health outcomes may also vary by chronic disease or class of diseases. Future work may consider examining relationships between cost of care-related communication, self-management behaviors, and health outcomes in other chronic disease populations.

Behavioral Interventions

Implications for behavioral interventions are evident for both patients and health care providers. PPACA reforms will provide abundant opportunities for individuals to make their health care more affordable or acquire health insurance. This includes expansions of safety net programs such as Medicaid, as well as insurance exchanges, premium subsidies and cost-sharing assistance. Reforms assure greater transparency of information for patients to better navigate the health care system. However, given the high prevalence of inadequate health literacy, vulnerable populations may continue to face access barriers, and an immediate need for behavioral interventions to help individuals with chronic conditions navigate complex systems may be required.

For interventionists, peer-led groups may present an effective modality for teaching individuals with cost-related concerns how to initiate and engage with their provider in discussions about cost and how to self-advocate for affordable options. If patient initiation of cost-related discussion increase, clinicians' ability to address these concerns will be needed.

One step towards increasing the evidence-base for routine practice of cost of care-related communication between clinician and patient is to develop and evaluate clinician interventions that aid in seamlessly incorporating such discussions into practice. Such interventions would teach health care providers how to engage in potentially sensitive discussions with their patients about cost and affordability, and how to clarify or intervene on their perceptions of financial burden. They would also evaluate the impact of communication on patient health outcomes. The first step in this area would be to determine best practices for initiating and engaging in cost of care-related discussions with patients, and then develop and pilot an educational program that would be receptive to clinicians.

Conclusion

Less than half of the sample reported discussing the cost of their asthma care with their health care provider, although more than three quarters of participants reported preferences for such discussions. Economic, demographic and clinical differences were evident between individuals with asthma who do and do not have such discussions with their health care providers, and the majority of patients initiate the conversation. Data and research design limitations may have precluded finding significant associations between cost of care-related communication, and self-management behaviors and asthma-related urgent care use. Despite these limitations, patients are interested in low-cost options and a venue for addressing their concerns with a care provider, therefore a greater understanding is needed in how to effectively and efficiently integrate these conversations into the delivery of health care.

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CHAPTER 7

CONCLUSION

Health-related financial burden has been affecting individuals in the U.S since the 1920's, when the relative cost of medical care began to rise (Cohn, 2008). It has grown to epidemic proportions over the last few decades. This is not a new problem; it has only increased in magnitude with the rise of a population managing multiple and complex chronic morbidities. However, only recently has it begun to be studied as a public health problem in which prevalence is high, disparities and adverse outcomes are evident, and numerous amounts of anecdotal evidence suggest that financial burden (perceived and actual) reduces the health status and quality of life of individuals and families (Cohn, 2008). It is also only even more recently that communication has begun to be studied as having a potential impact on the burden that the cost of medical care imposes on patients.

This dissertation provides several strengths and unique contributions to the literature. This dissertation provides an articulated conceptual model that conveys how perceptions of financial burden, communication between clinician and patient, and outcomes interact. This dissertation provides evidence of pathways through which patient characteristics influence *perceptions* of financial burden among a high-risk population and preferences for cost of care-related communication with a care-providing clinician. It provides support that economic factors (household income, health insurance, and out-of-pocket expenses) account for the relationships between patients' clinical and demographic characteristics and their perceptions of financial burden and preferences for communication to mitigate burden. The findings reinforce the fact that many people perceive financial burden, despite having resources to access care, and would like to discuss cost with their health care provider, but that these discussions occur infrequently. This dissertation confirms that a preference for such discussions is quite high in a high-risk population and more often patients are initiating the discussion more than clinicians. This dissertation is the first exploration of cost of care-related communication from the patient perspective in the context of asthma. Findings from this dissertation begin to allow speculation that the changing economic climate may also be changing the utility of factors that often provide economic security and typically give rise to socioeconomic mobility, such as marriage, education and, employment. This dissertation confirms that perceptions of financial burden and preferences for communication manifest across all types of health insurance and no insurance, and level of income. This dissertation is the first to contribute an in-depth understanding of aspects of disease management that individuals with asthma perceive financially burdensome, and what perceptions of burden entails as appraised by patients themselves. This dissertation recognizes that the relationships between cost of care-related communication, self-management behaviors, and health outcomes are complex, may not be unidirectional, and require a better understanding of what effective communication about cost entails and with whom these conversations are most productive. In this vein, this dissertation recognizes the need for further research to specify, quantify, and estimate dynamic conceptual processes. Most importantly, findings from this dissertation suggest that economic resources do not necessarily protect individuals from perceiving financial burden with their health care, therefore a wide range of the population with chronic diseases may be at risk for poor health outcomes since perceptions strongly influence behavior.

Several broad limitations were revealed across the three studies that have implications for the interpretation of the aforementioned findings. This dissertation used secondary data. As a result, the items may have been measured differently than anticipated, limited to what already existed, or may be incomplete.

Qualitative investigations support the claim that conceptual relationships of factors and influences of cost of care-related communication may be more dynamic and complex than what concurrent mixed methods approaches can capture. Although the qualitative findings suggest that talking to the doctor about cost was helpful to participants, the lack of association between cost of care-related communication, self-management behaviors, and urgent care may benefit from more conceptual clarity regarding the relationships between these variables and other potential mediators, as well as what productive communication entails and with whom. The conceptual relationships in this dissertation were also assumed to be unidirectional but qualitative examples suggest non-recursive and interactive relationships may exist between factors.

Second, SEM procedures, including path analysis, require measures to have strong psychometric properties to ensure stable statistical estimation (Kline, 2011). The psychometric properties of several key measures in this study were not known, including perceptions of financial burden, preferences and frequency of cost of care-related communication, and self-management behaviors. Additionally, measures may be vulnerable to social desirability, or lack a full conceptual understanding of the construct of interest. Measures also did not capture the quality or the content of the communication occurring between clinician and patient about cost, and this information may be imperative in understanding associations to health outcomes.

With respect to the qualitative data collection obtained through focus groups, social desirability and the group format may have precluded individuals from sharing their true experiences with perceived financial burden, communication with their health care provider, their asthma self-management behaviors, and experiences with asthma-related urgent care. Because the in-depth interviews were a secondary analysis, they precluded eliciting in-depth information about constructs examined in this study beyond what was already available.

The data in this dissertation were cross-sectional. Therefore, the true direction of association and temporal sequencing between some variables may not be easily discerned.

Lastly, the study sample comprised African American women receiving care in Southeast Michigan. As a result, findings may not be generalizable to all women or all adults with asthma or those receiving care in other regions. Because inclusion criteria for the study required participants to receive care for their asthma, the number of individuals who reported not having a health care provider for their asthma may be greater than reported in this dissertation.

Implications for future research, health education and behavioral interventions, and clinical practice

Population and economic trends both domestically and internationally provide support that improving the delivery of healthcare is important to the viability of systems to care for a global population with increasing ailments. Health care spending in most Organization for Economic Co-operation and Development (OECD) countries is rising faster than overall economic growth (Schoen et al., 2010; Anderson & Frogner, 2008); many countries with universal coverage may need to start offsetting some of these costs directly to patients. This is already occurring in Australia, where rising co-payments for medications and private medical consultations, and eligibility barriers for existing social supports are making chronic illness management economically stressful, especially for those with low incomes and the retired (Essue, Kelly, Roberts, Leeder, & Jan, 2011).

In the U.S. alone, one out of every two adults and 25% of children has a chronic disease; one out of five adults has multiple chronic conditions. The recent passage of the Patient Protection and Affordable Care Act (PPACA) will provide millions of uninsured Americans with health insurance coverage. Cost, quality, and access challenges will still persist with the PPACA reforms, and this underscores the importance of developing and enacting low-cost healthcare delivery solutions to improve the quality of care and lower overall costs. Strengthening clinician-patient partnerships through effective communication is one potential low-cost solution towards this end.

For individuals with chronic conditions, health insurance provides access to reasonably priced routine care to prevent serious medical crises that prove more costly to both individuals and society when treated in urgent care settings. However, actuarial principles that underlie health insurance, based on the pooling of risk to balance and offset costs, assure that an increasing population with chronic disease will continue to make out-of-pocket expenses a common reality for those utilizing health care services. Patients' out-of-pocket expenses will be evident regardless of the provision of health insurance, the kind of health insurance, and the availability of federal subsidies through recent reforms. Medical innovation has allowed individuals to live longer and active lives with chronic conditions. How such innovation is effectively delivered to patients requires a stronger evidence-base. Communication of affordability and access to therapies must play a critical role in healthcare delivery to ensure the best therapies are reaching patients. Hence, how patients' concerns with their out-of-pocket expenses can be integrated and addressed in routine patient-centered care to improve care quality constitutes a research and practice priority. Improving communication between clinician and patient is of interest to many stakeholders, as reforms of provider incentives with the PPACA move toward rewarding clinicians for prevention and the quality of care they deliver.

The findings from this dissertation have a number of implications for clinical practice, future directions in research, and the development of behavioral and health education interventions. The next logical steps of this research are to 1) acknowledge and address patient preferences and perceptions with the financial-related challenges associated with their chronic condition now, and 2) strengthen the evidence-base for wider dissemination of cost of care-related communication as a health care delivery solution through research and intervention development.

Clinical practice

While some practice settings may prefer to triage concerns about costs to social workers, finance departments, or support staff, the implications of the findings of this dissertation are most relevant to clinicians who prescribe therapies, and make diagnostic and treatment recommendations. Since clinicians provide therapeutic recommendations and play an instrumental role in facilitating chronic disease management, especially among individuals with asthma, the findings presented in this dissertation provide opportunities for initiating communication between provider and patient at the point of care.

Health care providers may be able to better understand how perceptions of financial burden may manifest for their patients, regardless of the type of health insurance coverage their patients' have or clues that may suggest their ability to pay. Clinicians may be more aware of the out-of-pocket expenses their patients are incurring, especially as a result of the volume of medications prescribed and whether their medications are offered on the formulary of their health insurance. This may provide a window of opportunity to elicit information to engage in potentially sensitive discussions regarding affordability. They may also be aware of challenges with continuous coverage or false bills that patients face, regardless of the type of health insurance coverage they have.

Strengthening and improving health care delivery and lowering overall health care costs requires behavior change. There is good reason to increase cost of care-related communication in an efficient way now; even if doing so may not significantly affect patients' self-management or health care use. First, patient preferences are not being fully met, therefore engaging patients in conversations around factors that may impact their ability to manage their health becomes imperative in providing patient-centered, quality care. Second, patients need to communicate with health care providers in order to access affordable options (e.g. free samples, verification to access community assistance programs). Third, such communication could potentially include behavior change, particularly with providers, to reduce overall health care costs and improve patient health. Decision-making in medical training is often guided by the notion that when in doubt, more health care is better, regardless of whether more care contributes to gains in health status. Provider-induced demand (which is one part of a larger issue of supply-induced demand, in which the availability of more resources influences utilization), where health care providers encourage patients to consume services that patients would not have otherwise chosen had they been fully informed, is particularly apparent in the management of chronic diseases (Dartmouth Atlas of Healthcare, 2007). This behavior has led to large regional variation in health care spending and contributes to wasteful healthcare expenditures without evidence of improving patient health (Dartmouth Atlas of Healthcare, 2008). Subsequent increases in the already catastrophic U.S. healthcare deficit raises and shifts healthcare costs to consumers. Engaging in cost-related discussions with patients may potentially self-regulate health care providers to provide cost-efficient, evidence-based care.

Some patients recognize that they can negotiate the cost of their healthcare, therefore clinicians may need to be prepared to engage in such conversations with their patients. Some patients are interested in low cost options, therefore clinicians may also prepare their practice settings to have information on such options readily available. This includes information on accessing samples or community assistance programs. These recommendations require democratizing clinician-patient relationships. As previously mentioned, health care reform is migrating towards aligning provider incentives with quality and better patient outcomes, therefore engaging patients as a full partner in their care will become critical for providers in the care they deliver.

Health education and behavioral interventions

Implications for behavioral interventions are evident for both health care providers and patients.

One step towards increasing the evidence-base for routine practice of cost of care-related communication between clinician and patient is to develop and evaluate clinician interventions that aid in seamlessly incorporating such discussions into practice. Such interventions would teach health care providers how to engage in potentially sensitive discussions with their patients about cost and affordability, and how to clarify or intervene on their perceptions of financial burden. They would also evaluate the impact of communication on patient health outcomes. The first step in this area would be to determine best practices for initiating and engaging in cost of care-related discussions with patients, and then develop and pilot an educational program that would be receptive to clinicians.

For patients, a number of opportunities for behavioral and health education interventions are evident. Qualitative findings revealed that community assistance programs can be difficult to navigate. Health education interventions may be designed, with particular attention to health literacy and numeracy, to provide more awareness of such programs and outreach to individuals with chronic conditions, especially vulnerable populations. Such interventions may also increase ease of navigating community assistance programs, and as well as navigating new information systems that accompany PPACA reforms. These new systems include the health insurance exchanges, coverage options for public health insurance programs, and public reporting of quality metrics of health care providers.

Peer-led groups may be an effective modality for teaching individuals with cost-related concerns how to initiate discussions and engage with their provider regarding cost and how to self-advocate for affordable options. As previously mentioned, a first step towards this end would be to develop and pilot such programs for patients.

Research

Given the limited time often afforded to clinicians to spend with their patients, utilizing visit time with approaches that have the greatest impact on patients' health outcomes becomes critical. In order to promote and widely implement the discussion of cost between clinician and patient as an important health care delivery solution, development of the evidence-base that can speak to the effectiveness of such discussions is necessary. Such an evidence-base will need to clarify the relationships between cost-related discussions and meaningful patient health outcomes such as improved disease control, decreased urgent care use, patient satisfaction, and patients' quality of life. More evidence is needed in understanding what entails quality and sufficient communication about cost between clinician and patient and how care teams can efficiently manage such concerns given varied expertise around the financial aspects of disease management. For some clinicians and practice settings, incorporating such discussions as part of routine care may compete with the inertia of previous practice; therefore, strengthening the evidence-base will be imperative to changing clinical practice.

The findings from this dissertation have several implications for future research that engage multidisciplinary teams including social and behavioral scientists, clinicians, economists, as well as survey, health services, policy, organizational and communications researchers. Mixed methods approaches are imperative to clarifying our conceptual understanding of the constructs presented in this dissertation and the conceptual pathways through which they are related. Future research should continue to utilize multiple formats of qualitative data collection, given limitations that social desirability pose in group formats and the opportunities to obtain a deeper understanding of individuals' experiences through individual interviews. Future studies may consider sequential mixed methods study designs whereby qualitative data inform conceptual linkages and alternative models, the development of quantitative measures, data collection and analysis before hypothesis testing. This includes eliciting clinician perspectives and incorporating relevant clinician factors (e.g. specialty, practice settings) into analyses in order to strengthen the evidence-base for intervention.

Future research may continue to refine measures, especially for perceptions of financial burden, patients' out-of-pocket expenses, cost of care-related communication, and self-management behaviors. Given that prior work has defined and measured health-related financial burden through varied approaches, it is imperative that future work distinguishes between perceptions of burden based on individuals' own appraisals, and actual financial burden based on individuals' resources. Patients' burden may also include the retention and acquisition of economic sources. Assessing the fluidity of perceptions of financial burden over time is an opportunity for further exploration. A multi-item measure may better capture varied experiences with perceptions of financial burden, rather than a single-item measure. Life course perspectives in this area may contribute to measurement development. Cost of care-related communication may also gain from further measurement clarity, with emphasis on methods that capture the nature of the dialogue and clarification on what constitutes a successful dialogue around cost as perceived by both patient and clinician.

Individuals' adaptive experiences with perceptions of financial burden also deserve further inquiry; particularly the effects of coping efforts on physical health. The effects of psychosocial stressors on physiological health outcomes has been widely described and studied (Geronimus, Hicken, Keene, & Bound, 2006), as have the negative impacts of high-effort coping on physiological health (James, 1994). However, little is known about the differential effect of coping with perceptions of health-related financial burden on such physiological processes. Investigating these processes in high-risk populations would strengthen the evidence-base for intervention.

This dissertation focused on the management of asthma. Future research may consider comparing and contrasting the relationships studied in this dissertation across other populations, other costly chronic diseases or among groups with multiple morbidities. Individuals with diabetes and cancer, for example, face high out-of-pocket expenses in managing their conditions due to complex management regimens and expensive treatments (Smith-Spangler, Bhattacharya, & Goldhaber-Fiebert, 2012; Meropol et al., 2009). Further investigating perceptions of financial burden and cost of care-related communication in other high-risk populations may provide further support and new insights into the pathways examined in this study. It would also be useful to further identify and study other population subgroups that face the greatest barriers accessing existing resources to manage the costs associated with chronic conditions. Communication with a health care provider may be the best option for such individuals, as existing programs and policies may be out of their reach.

PPACA reforms will provide abundant opportunities to explore patient perceptions' with maintaining affordable coverage. Future research may continue to examine patient perceptions of financial burden with implementation of these new policies. This includes experiences with safety net programs such as Medicaid, as well as experiences with insurance exchanges, access and utility of premium subsidies and cost-sharing assistance. Reforms assure greater transparency of information for patients to better navigate the health care system. Assessing patients' perceptions of transparency provides other opportunities for research.

Future research may also consider other analytic techniques that fall within the SEM family to examine pathways to perceptions of burden. One example is the use of latent factors to estimate the unique contribution of constructs that may pose measurement limitations such as perceptions of financial burden. Lastly, although the development of fit statistics is an active research area in SEM, more work towards developing fit statistics for count outcomes is imperative in order to aid researchers in discerning relationships between cost of care-related communication and meaningful health outcomes that are rare events. Although fit statistics in general in SEM pose several limitations (Kline, 2011), at the very least, they provide a cue for diagnostic investigation that may be helpful early in analytic stages because they indicate discrepancies between the model and data.

Productive management of chronic disease requires clinicians and patients to work in partnership. Perceptions of burden and preferences to discuss cost are not exclusive to individuals of low socioeconomic position or entirely a function of their existing resources. The recognition of individuals’ concerns with affordability and access to disease management resources and communication of such concerns may strengthen clinician-patient partnerships and assist individuals to lead full and active lives.

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