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"You Have to Rob Peter to Pay Paul So Your Kid Can Breathe"

Using Qualitative Methods to Characterize Trade-Offs and Economic Impact of Asthma Care Costs

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Background: Economic analyses often focus narrowly on individual patients' health care use, while overlooking the growing economic burden of out-of-pocket costs for health care on other family medical and household needs.

Objective: The aim of this study was to explore intrafamilial trade-offs families make when paying for asthma care.

Research Design: In 2018, we conducted telephone interviews with 59 commercially insured adults who had asthma and/or had a child with asthma. We analyzed data qualitatively via thematic content analysis.

Participants: Our purposive sample included participants with high-deductible and no/low-deductible health plans. We recruited participants through a national asthma advocacy organization and a large nonprofit regional health plan.

Measures: Our semistructured interview guide explored domains related to asthma adherence and cost burden, cost management strategies, and trade-offs.

Results: Participants reported that they tried to prioritize paying for asthma care, even at the expense of their family's overall financial well-being. When facing conflicting demands, participants described making trade-offs between asthma care and other health and nonmedical needs based on several criteria: (1) short-term needs versus longer term financial health; (2) needs of children over adults; (3) acuity of the condition; (4) effectiveness of treatment; and (5) availability of lower cost alternatives.

Conclusions: Our findings suggest that cost-sharing for asthma care often has negative financial consequences for families that traditional, individually focused economic analyses are unlikely to capture. This work highlights the need for patient-centered research to evaluate the impact of health care costs at the family level, holistically measuring short-term and long-term family financial outcomes that extend beyond health care use alone.

Key Words: economic outcomes, out-of-pocket costs, insurance, family, asthma

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Commercial insurance designs with high deductibles have placed increased responsibility on patients for out-of-pocket costs for health care services. High out-of-pocket health care costs are a source of financial strain for many patients and can lead to unmet health care needs,[1–5] especially for those with chronic conditions like asthma.[6–9] Research on health insurance policy and economic outcomes is often focused on individual patients, usually adults, but many people obtain insurance as a family. Patients make health care and financial decisions based on other competing family medical and nonmedical needs.[10–12] Health care decisions for individual patients involve implicit and explicit trade-offs to balance each family member's health care needs and costs against a family budget.

Studies on intrafamilial trade-offs related to health care have focused mostly on the health and economic consequences of caregiving.[13,14] Fewer studies have explicitly addressed trade-offs that occur within families due to out-of-pocket health care costs. Economic pressures and high out-of-pocket costs

within the family have been associated with delayed/forgone care for other family members.[10,12,15] Parents may prioritize their children's health care over their own when faced with financial pressures,[12,16] or prioritize the health care needs of chronically ill members.[1] These studies suggest intrafamilial economic trade-offs but do not shed light on how these decisions are made or which outcomes are prioritized.

Asthma is an exemplar condition through which to examine intrafamilial economic trade-offs. Asthma is a major cause of preventable disease burden for adults and children, with significant socioeconomic disparities.[17–19] Asthma medication adherence is suboptimal, placing patients at risk for disease exacerbations.[20–23] High out-of-pocket costs can limit patients' access to needed medications for asthma and have been associated with adverse asthma outcomes for children and adults.[7,24–27] In 2018, mean annual out-of-pocket costs for patients with asthma exceeded $1000 and the price of a controller inhaler was $292–$496.[9] In more recent years, the availability of new biologic medications may increase asthma costs,[28] tempered by the availability of generic versions of some inhalers.[29]

It is important to understand how patients with chronic conditions like asthma make intrafamilial trade-offs in response to health care cost burden. Recognizing the types of health and economic outcomes that matter to families and family-level dynamics in their decision-making provides crucial information for building data capacity for patient-centered outcomes research. Using asthma as a model, the goal of this study was to qualitatively explore intrafamilial trade-offs made by commercially insured patients when making decisions about paying for asthma care.

METHODS

Design

As part of a larger mixed-methods project, we conducted a qualitative thematic analysis of in-depth interviews with commercially insured adults who had asthma, were the parent of a child with asthma, or both. Drawing from the traditional of naturalistic inquiry,[30] this study used a qualitative approach to identify patient-reported issues, priorities, decision-making approaches, and intrafamilial trade-offs that are not often captured in existing datasets derived from surveys or medical claims. Qualitative approaches are underused in health economics but can reveal contextual gaps in quantitative data and identify areas in which to focus measure development and data linkages.[31]

Participants

We conducted interviews in 2017–2018 with commercially insured adults who obtained insurance through an employer, the Affordable Care Act (ACA) Marketplace, or directly from an insurance carrier. Eligible participants were: (1) aged 18–64 years; (2) English speaking; (3) continuously enrolled for at least 12 months in a commercial insurance plan; and (4) diagnosed with asthma and/or the parents of children, age 4–17, diagnosed with asthma. Single adults (families of one) were included in addition to those sharing insurance with other family members.

We recruited participants from 2 sources. First, we used claims data from Harvard Pilgrim Health Care (HPHC), a not-for-profit insurer covering over 1 million members living primarily in New England. We flagged members if they or their children had at least 1 inpatient, emergency department, or outpatient claim in the prior 2 years with a diagnosis code for asthma, and invited identified them to participate by mail and phone. Second, to increase the demographic and insurance plan diversity of our sample, we recruited participants with the Asthma and Allergy Foundation of America (AAFA), a national asthma advocacy organization. We invited participation via postings to AAFA's Asthma Online Community, email listserv, newsletters, and flyers. We confirmed a diagnosis of asthma and the eligibility of all participants before enrollment using a standardized screener.

Our purposive sample included participants with high-deductible health plans (HDHPs) and low or no deductible plans. We defined HDHPs as having annual deductibles of $\geq$ $1000 per individual or $2000 per family,[32,33] and did not restrict to Health Savings Account-eligible HDHPs with standardized deductible policies.[34] We also sought to maximize variation in terms of identified asthma patient (self/parent/both), asthma severity, race/ethnicity, and household income. We determined our sample size of 59 participants by thematic saturation, which occurred when the final 6 interviews failed to yield information that meaningfully enriched our themes.

Data Collection

Four investigators trained in qualitative research methods (a physician, a behavioral scientist, a sociologist, and a public health professional) conducted telephone interviews that lasted 39 minutes on average (range: 20–68 min). Interviewers used a semistructured interview guide consisting of open-ended questions designed to explore the impact of asthma on participants' daily lives as well as their experiences using their insurance to manage asthma care costs. In addition, participants provided data on demographics and asthma severity through responses to closed-ended survey questions. Members of the project's Patient and Family Advisory Council piloted the interview guide and survey questions before fielding. Interviews were audio-recorded and transcribed verbatim. Participants provided verbal informed consent and received a $50 gift card for participation. The HPHC Institutional Review Board approved the study protocol.

Analyses

We analyzed data iteratively via thematic analysis in the manner described by Patton[35] to describe strategies participants used to make intrafamilial trade-offs needed to manage the cost of asthma care. In the first, inductive phase of analysis, 4 investigators independently coded a subset of 4 interviews to identify data related to cost trade-offs. Through comparison and discussion, we refined our definition of this overarching code, and 2 investigators practiced applying it to transcripts independently until we reached a high level of agreement (97%), using the percent agreement measured by NVivo (Version 12; QSR International) for comparing each coded "turn" that a participant spoke at one time. One investigator then applied the cost trade-offs code to all transcripts systematically using

NVivo. A second investigator reviewed the coded transcripts to identify disagreements in coding, which the team resolved via discussion.

We next repeated this process to conduct more fine-grained coding within the cost trade-offs data. Two investigators re-read transcripts to generate 5 codes and a corresponding standardized codebook. These codes were related to how participants perceived the value of asthma care in their finances, as well as strategies they used to make cost trade-offs according to their goals, family roles, health condition characteristics, and perceptions of treatment effectiveness (Table 1). One investigator applied these codes, and a second reviewed the coded transcripts to identify, discuss, and resolve disagreements in coding.

In the second, deductive phase of analysis, we considered data within each code to elucidate emerging patterns. We described the resulting themes, selecting representative quotations to illustrate each. Finally, members of the study's Patient and Family Advisory Council provided feedback on preliminary findings to improve relevance and clarity of our subsequent manuscripts and report.

RESULTS

Participant Characteristics

Our study sample (n = 59) included participants who had asthma themselves (46%), were the parent of a child with asthma (29%), or both (25%) (Table 2). The majority were female (85%), and most identified as non-Hispanic White (76%), non-Hispanic Black (10%), or Hispanic (10%). Three quarters of participants had health insurance plans with high deductibles (75%), and one fifth (20%) had annual household incomes <$50,000.

Cost Trade-off Themes

We identified 6 themes related to intrafamilial trade-offs related to asthma care costs, described below with additional quotations in Table 3.

Families Placed a Very High Priority on Paying for Asthma Care

Many participants expressed the view that paying for asthma care was unavoidable and non-negotiable because of the seriousness of their asthma and their desire to prioritize health, or because their doctor said it was important.

"I know I'm on some pretty expensive medications, but without [them] I'd be not leaving my house ever or my bed probably … you end up paying [the high cost] just because you need it to breathe."—Adult with asthma

Participants described making what were sometimes substantial sacrifices to pay for a family member's asthma care. These included financial sacrifices such as unpaid bills, incurring credit card debt, or enrolling in payment plans, and personal sacrifices such as spending less on essentials like food, working extra hours, and even in 1 case, selling plasma.

Families Prioritized Short-term Survival Over Longer Term Health and Economic Well-being

Despite their intent to prioritize asthma care, participants reported having to put off obtaining asthma care or filling prescriptions to pay for pressing essentials like rent, food, or electricity.

"You got to pay your rent … So there were times when the rent had to be paid and the medications couldn't be."—Adult with asthma

Situations calling for trade-offs were fluid and varied over time, depending on whether families had met their deductible, when they expected their next paycheck, and whether their asthma care required an upfront payment (eg, a prescription) versus something that could be billed later (eg, an emergency department visit). These delays could be temporary rather than completely forgone care. For example, once the rent was paid and the next paycheck came, they filled the delayed prescriptions. Others traded off items that were nonessential in the short term but detrimental to their future financial well-being, such as taking money from savings or not contributing to a college or retirement fund. Trade-offs could also involve forgoing less essential nonmedical items to pay for asthma care, such as "extras" like going out to dinner, taking vacations, or having cable.

TABLE 1. Mapping of Cost Trade-off Codes and Themes

Code	Code definition	Theme
Relative value of asthma care in family finances	Financial prioritization of asthma care compared with other health care needs	(1) Families placed a very high priority on paying for asthma care
Prioritization of short- and long-term goals	Trade-offs in health care decision-making over time Includes related consequences for health and finances	(2) Families prioritized short-term survival over longer term health and economic well-being
Prioritization by family role	Trade-offs in health care decision-making among family members	(3) Families prioritized health care for children over adults
Prioritization by health condition characteristics	Trade-offs in health care decision-making between asthma and other health conditions Includes comparisons for individuals with multiple conditions, as well as comparisons across family members	(4) Families prioritized costs based on the seriousness or acuity of the health condition
Prioritization by treatment characteristics	Trade-offs in health care decision-making by perceptions of treatment availability and effectiveness	(5) Families prioritized the treatment they perceived to be more effective (6) Families de-prioritized treatments when they perceived having a lower cost alternative available

TABLE 2. Characteristics of the Study Population

	n (%)
Total	59 (100)
Female	50 (85)
Age (y)	
18–39	20 (34)
40–64	39 (66)
Race/ethnicity	
White, non-Hispanic	44 (76)
Black, non-Hispanic	6 (10)
Hispanic	6 (10)
Other	2 (3)
Annual household income <$50,000	11 (20)
US region of residence	
Northeast	34 (58)
Midwest	10 (17)
South	10 (17)
West	5 (8)
Insurance plan type	
High deductible	44 (75)
Low or no deductible	15 (25)
Family member with asthma	
Participant	27 (46)
Child	17 (29)
Both	15 (25)
Asthma severity*	
Persistent	38 (64)
Nonpersistent	21 (36)
Recruitment source	
Harvard Pilgrim Health Care	33 (56)
Asthma and Allergy Foundation of America	26 (44)

*Assessed via 3 items derived from the US National Asthma Education and Prevention Program. In the case of multiple family members with asthma, the respondent provided data on the family member whose asthma was most severe.

Families Prioritized Health Care for Children Over Adults

A number of participants felt their children's asthma care needed to be their priority as a parent and that it was a given that their child's asthma care should come first. Parents reported sacrificing their own health care needs or incurring debt to pay for their child's asthma care.

"We definitely prioritize the kids over us. I don't often go to the doctor because I know we're spending so much on them."—Parent of child with asthma

However, even those who expressed a priority for their children's asthma care acknowledged delaying filling a prescription when they did not have the money available. Being unable to prioritize a child's asthma care because of financial constraints was particularly upsetting to parents and threatened their perception of being a good parent.

Families Prioritized Costs Based on the Seriousness or Acuity of the Health Condition

For example, when faced with cost constraints, families might chose to pay for asthma medication over medication for another chronic health condition that was less symptomatic.

"Usually, I judge it by the health that I'm in, and where I'm at. If I'm not having a hard time with the asthma, then I'll do the other [high blood pressure medication], and vice versa." —Adult with asthma

Other families chose to pay for asthma medications for the family member with more severe asthma over the one with milder intermittent asthma.

Families Prioritized the Treatment They Perceived to Be More Effective

When faced with paying for multiple medications, patients chose the one they perceived to be of greatest relative benefit in that particular situation.

"So I ended up not getting the Tamiflu because it was way too expensive and I couldn't afford it in order to get [the asthma medications] the doctor and I thought would really help her right now."—Parent of child with asthma

Families also reported trading off between asthma controller and rescue medications depending on which they felt was more helpful for their asthma.

Families Deprioritized Treatments When They Perceived Having a Lower Cost Alternative Available

For example, families chose not to fill allergy medications or obtain an EpiPen because they believed they could avoid allergy triggers instead. Others chose not to fill their own rescue inhaler because they could share with a family member.

"I can put off [getting] the albuterol [for myself] because [my son] gets it. So if I need it, I can use his."—Adult and parent of child with asthma

DISCUSSION

This qualitative study of families affected by asthma across the United States found that when faced with asthma care costs and competing demands, families tried to prioritize asthma care over other competing medical and nonmedical needs, often with negative financial consequences. These intrafamilial trade-offs were necessary, in part, due to dynamic financial circumstances that could require temporarily forgoing asthma care to balance other important health and financial factors in the family at that moment. We found that families employed different strategies to make these difficult choices, using criteria that attempted to balance overall family benefits and costs by prioritizing short-term survival, children's health care, more acute conditions, more effective treatments, and treatments without lower cost alternatives.

This study provides new evidence demonstrating the intrafamilial effects of financial burden from health insurance cost-sharing. We found that health care decisions for one individual have spillover effects on the rest of the family and conversely, that family out-of-pocket cost burden can affect health care decisions for an individual member. These findings add to the prior literature that suggests that high family out-of-pocket costs are associated with unmet health care needs for individual family members,[4,16] and that an individual family member's illness can lead other family members to neglect their health, incur debt, and deplete

TABLE 3. Findings of Participants' Experiences With Intrafamilial Trade-offs Due to the Costs of Asthma Care

Theme	Supporting quotation	Implication for patient-centered economic data collection
(1) Families placed a very high priority on paying for asthma care	"You've got to figure out the best thing to do based on her [child's] health and figure out how to pay the bill later."—Parent of child with asthma "You have to rob Peter to pay Paul so your kid can breathe"—Adult with asthma "On the other insurance plan it was 600 dollars a month for all of her medication, so we had to work around that and prioritize our expenditures in order to make sure that we got that medication. And then we would cut back in other areas."—Adult with asthma whose wife also has asthma "It's hard to buy food when you have to buy a nebulizer but you need the nebulizer and that's $100, $150 depending."—Adult and parent of child with asthma "There have been times where I may not have the funds [to afford asthma care], so what I do on the side is I go and donate plasma … and that money that I get from that plasma [can be used if I need] Symbicort or Ventolin"—Adult with asthma	Measure out-of-pocket health care costs Measure nonmedical economic outcomes
(2) Families prioritized short-term survival over longer-term health and economic well-being	"It's mortgage, food, medication. So [asthma medication] would be third on the list…You know, [we've] got to have a roof over our heads and of course, food. And then it's medication and like I said, I've had to push medication aside sometimes and say, 'I can't get that right now.' Dulera is like $300 dollars."—Adult and parent of child with asthma "When we're at the end of the year [and] we've already met our deductible, I don't think twice about going to the ER or the doctor [for asthma treatment]. But in January when we haven't paid [the deductible] yet, the cost is a factor for me."—Parent of two children with asthma "It's a lot of money that could be going into savings … it's not so much a phone bill not being paid; it is, "Oh, I didn't max out my IRA contribution this year … because I didn't have the money." … So, a lot of our retirement savings and things like that take a backseat. So savings is nonexistent."—Adult and parent of child with asthma "Every month it's going to be about $120 which can decrease how often I'll go out and socialize with friends because it will just be cheaper to stay at home or maybe I won't drive around as much so I can save money on gas and put money towards my medication."—Adult with asthma	Measure nonmedical economic outcomes Use longitudinal micro-costing approaches to capture temporary financial crises Track economic well-being over longer time horizons
(3) Families prioritized health care for children over adults	"When it comes to my kid, he always gets his medicine. When it comes to me, I'll buy what I need, what will work for now. And then whatever else I need, I just wait for my next check."—Adult and parent of child with asthma "As far as [my son's] medications, I would not eat before I didn't get his medicine. You know what I mean, you have to have it. [But] have we had to wait a couple days to pick up an inhaler? Absolutely."—Parent of child with asthma "Sometimes you feel like a bad parent. Like I should be able to buy her $400 worth of medication if it's going to make her better, but in reality you can't. Sometimes you just can't. It tugs on your heartstrings a little bit, too."—Parent of child with asthma	Include family members Measure out-of-pocket health care costs Measure nonmedical economic outcomes Use longitudinal micro-costing approaches to capture temporary financial crises Measure revealed preferences
(4) Families prioritized based on the seriousness or acuity of the health condition	"The other day [my husband] had a medicine, and he goes, "Well, I'm just going to wait like another week, because I'm really doing okay." But I think he delays care more than me, and I kind of don't do that, because my asthma's crucial to have control. So I think he kind of has to throw things my way a little bit so that I have asthma control rather than seeing me ill."—Adult with asthma "I'm not going to die if I don't have my inhaler but the medication my wife takes definitely is keeping her alive or at least it keeps her quality of life halfway decent."—Adult with asthma whose wife also has asthma	Include family members

(*Continued*)

TABLE 3. Findings of Participants' Experiences With Intrafamilial Trade-offs Due to the Costs of Asthma Care (*continued*)

Theme	Supporting quotation	Implication for patient-centered economic data collection
	"Usually, I judge it by the health that I'm in, and where I'm at. If I'm not having a hard time with the asthma, then I'll do the other [high blood pressure medication], and vice versa."—Adult with asthma "The asthma medication kind of takes priority over the celiac, just because celiac—I mean, she'll feel kind of crappy for a little bit and have to recover, but asthma—if it goes for too long it's a trip to the ER."—Adult and parent of child with asthma	
(5) Families prioritized the treatment they perceived to be more effective	"At the beginning of this year [my daughter] had the flu. … I was trying to get her …Tamiflu, an oral steroid and another inhaler. And the Tamiflu by itself was $150. And I was like, 'Does she really need the Tamiflu?' I can maybe do these other two prescriptions that will help her breathe and maybe her flu will last a little bit longer. So I ended up not getting the Tamiflu because it was way too expensive, and I couldn't afford it in order to get [the asthma medications] the doctor and I thought would really help her right now."—Parent of child with asthma "Singulair [a controller medication] is not, like, a real major thing for me right now. So if I needed my Ventolin or my albuterol [a rescue medication for flare ups, as] opposed to my Singulair, I won't get the Singulair."—Adult with asthma "I've picked what I feel is mostly needed, and that would probably be her inhaler [Flovent, a controller medication] …because it's a daily inhaler [rather than albuterol, an as-needed rescue medication]—Parent of child with asthma	Measure out-of-pocket health care costs
(6) Families de-prioritized treatments when they perceived having a lower-cost alternative available	"The ProAir [rescue inhaler] we don't go through that often, so I think I've filled it twice, because I also have the nebulizer [nebulized rescue medication] if things got bad, and the cost of that is minimal."—Parent of child with asthma "I had to get an inhaler from my sister because I didn't have the funds and everything like that. So I've left prescriptions sitting at Walgreens or sitting at Shop 'n Save or whatever because I didn't have the funds available, and I had to borrow an inhaler."—Parent of child with asthma "That's happened before, where I had to get my Ventolin [rescue] inhaler and my Dulera [controller medication] over taking maybe the EpiPen … Can I totally avoid not being stung by bees, preferably?"—Adult and parent of child with asthma	Include family members

assets.[11,36] Our results extend the existing literature by elucidating the decision-making criteria used to make intrafamilial trade-offs when faced with high out-of-pocket health care costs. These criteria weigh competing short-term and long-term health care and economic needs of other family members, including children. Other qualitative studies have outlined individual-level strategies to manage health care–related financial stress, including depleting savings and accruing debt to pay for health care, not obtaining medical care or filling medications because of financial concerns, and seeking lower cost alternative treatments.[37] Similar to our study, obtaining needed health care for children and for patients with more severe illness was prioritized over financial concerns.[38,39]

A number of policy interventions have the potential to address the negative ramifications of health care cost-related intrafamilial trade-offs. Efforts to control escalating drug prices and allow generic asthma medications could be beneficial.[29,40] The degree of health care cost burden could be reduced by policies like the ACA Marketplace's income-based premium and cost-sharing subsidies and value-based insurance designs, such as preventive drug lists, that reduce cost-sharing for high-value services.[41,42] Plans with smaller deductibles that reset over shorter time periods could shield families from large financial hits from unexpected health shocks.[43] Policies should consider the cost burden to families and not just individuals to avoid situations like the ACA's "family glitch" where thresholds for eligibility for subsidized coverage in the ACA Marketplaces was based on individual, not family, premiums.[44] Improving health insurance literacy and promoting cost discussions with providers could lead to more informed shared decision-making that anticipates the costs and intrafamilial spillover effects of different treatment plans.[45,46] Public programs that provide assistance with necessities like food and housing could reduce the competing priorities in family budgets that force trade-offs with health care needs.[47,48]

Implications for Patient-Centered Economic Data Collection

Our findings can inform efforts of this special issue of *Medical Care* to improve data capacity for patient-centered economic outcomes research. Our qualitative findings reveal financial factors that are salient to families and that drive their health care decision-making, which can inform the design and collection of quantitative economic outcomes; Table 3 describes specific implications of our findings for these efforts. This study indicates that such data should include family members and consider intrafamilial trade-offs regarding health care costs. Research that solely measures individual patients' health care use and economic burden will miss important intrafamilial factors that drive health care decisions.[11,49–51] Measuring intrafamilial health care trade-offs quantitatively requires linking individual patient data into family units based on shared insurance, address, or birth records,[2,52–55] or using household panel surveys.

Understanding health and economic outcomes that are most important to families in the face of conflicting household priorities can be challenging. In our qualitative study, parents expressed strong priorities for obtaining asthma care for children but acknowledged delaying asthma care for their child in the face of competing economic pressures. Social stigma surrounding health-related financial burden requires careful item construction for survey measures to elicit financially driven outcomes that are difficult to report. Given that trade-offs may not be explicit, it is important to measure revealed preferences using data about observed real-world health care choices and spending. Alternatively, if revealed preference data are not available or there are unobserved choices or outcomes, stated preference approaches such as discrete choice experiments are a robust and viable way to identify implicit trade-offs that families are willing to make.[56–58] While stated preference approaches are limited by their artificial nature and lack of real-world consequences for making the "wrong" choice, their strength is the ability to measure multiple-choice attributes that are difficult or costly to observe otherwise.[59] A combination of qualitative, survey, and preference-elicitation methods can efficiently identify key economic drivers and outcomes that are most salient to families that can then be measured at scale in secondary datasets.

Our study illustrates the need for patient-centered outcomes research to expand capacity to measure short-term and long-term economic drivers and outcomes that are meaningful to families. This includes measuring out-of-pocket health care costs and benefits information about cost-sharing requirements. The importance families placed on out-of-pocket spending speaks to the need to measure nonmedical economic outcomes like unpaid bills, debt, food insecurity, depleted savings, missed housing payments, or unpaid utilities, as well as overall levels of financial strain. Several single-item and multi-item measures of health care–related financial toxicity exist[50,51,60–62] but additional measures should be developed and validated to include family-level components and measure intrafamilial trade-offs. The fluid and situational nature of trade-offs reported in our study suggest the need to use longitudinal micro-costing approaches to capture temporary financial crises that would not be reflected in annual averages.[43] A longitudinal approach to data collection is important for tracking economic well-being over longer time horizons as families in our study made trade-offs that addressed pressing needs at the expense of harmful economic outcomes that would not manifest for many years.[11]

Policymakers need data on economic outcomes such as out-of-pocket spending, debt, and savings to inform decisions about strategies to make insurance and health care more accessible and affordable, especially during periods of economic downturn, such as during the COVID-19 pandemic. Without data on out-of-pocket spending and other economic outcomes, studies that measure health care utilization alone will miss important adverse effects of health insurance cost-sharing on financial outcomes that are compelling for patients and can negatively affect their well-being.

Limitations

We designed our study to capture the range of trade-offs families make to pay for asthma care, but our qualitative approach could not characterize the prevalence of these trade-offs. Our study focused on families with commercial coverage, where cost-sharing requirements and out-of-pocket costs are often much greater than in public insurance programs.[63] Although we used purposive sampling to enrich our sample, our findings may be less generalizable (or in qualitative terms, "transferrable") to understanding cost trade-offs for low-income and uninsured families. Our sample from AAFA may also be more engaged and informed than patients outside this community. We were not able to longitudinally assess how trade-off strategies were prioritized according to factors such as financial situation, specific insurance benefits policies, and family configuration that can vary over time, but this is an important area for future patient-centered economic outcomes research. Furthermore, this study focuses on families with asthma and could have more limited transferability to chronic conditions that may be less symptomatic (hypertension) or more life-threatening (cancer). However, the trade-offs described with health care for other conditions suggest that overarching themes of intrafamilial trade-offs transcend asthma. Given that asthma is a condition that is prevalent among both children and adults, it serves as an exemplar condition for understanding trade-offs between adults and children within a family and brings much-needed attention to the pediatric perspective.

CONCLUSIONS

Although patients with asthma prioritize obtaining care, out-of-pocket cost-sharing requirements may necessitate trade-offs within their families that compromise health or financial well-being. This work highlights the need for assessment of data from family members, including children, and additional family-level patient-centered economic outcomes to fully capture intrafamilial effects that drive patient decision-making, health care use, and health.

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