

Better Breathing or Better Living? A Qualitative Analysis of the Impact of Asthma Medication Acquisition on Standard of Living and Quality of Life in Low-income Families of Children With Asthma

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Abstract

Introduction—Purchasing children’s asthma medications places a burden on low-income families. The objective of this study was to explore how purchasing children’s asthma medications influenced household purchasing behavior and quality of life in low-income families with no drug insurance.

Method—Seventeen parents residing in the Greater Toronto Area with no drug plan and with household incomes below U.S. \$45,000 (twice the U.S. poverty level) participated. Semi-structured interviews were conducted, emphasizing the topics of prescription drugs used and cost versus effectiveness; purchasing behavior and drug administration; effects of medication purchasing on the family; and payment assistance. Transcribed narratives were coded and analyzed thematically.

Results—Annual expenditures for asthma drugs were U.S. \$300 to \$3000. Because asthma management was a high priority, foregone expenditures included paying for other family members’ health needs, essentials (clothing, food, better housing), and nonessentials (recreation, vacations) and long-term investments, such as their child’s future education and their retirement. Respondents believed quality of life was negatively affected.

Discussion—Not addressing the health concerns of family members, making sacrifices, and modifying investment decisions created sustained anxiety in families of children with asthma. Access to medication benefits would have a positive impact on quality of life. Health care providers can help to ensure that low-income families receive available assistance.

Asthma is the most common chronic disease of childhood in developed countries, with a prevalence of 10% to 18% (Lava, Moore, Li, & El-Sadaany, 1997). The annual cost per child with asthma varies from U.S. \$662 in older children with mild asthma to U.S. \$1850 in children younger than 4 years with severe asthma (Ungar & Coyte, 2001). Medications alone account for at least 20% of total costs for children with asthma (Lozano, Sullivan, Smith, & Weiss, 1999; Ungar & Coyte).

For many children, proper management requires treatment with multiple medications, including β -agonist bronchodilators and inhaled corticosteroids. The short-acting β -agonist bronchodilators (“relievers”) are effective at providing immediate relief during bronchoconstriction. The recommended use in children is as needed and prior to exposure to known triggers, such as cold air and exercise. Inhaled corticosteroids are anti-inflammatory agents (“controllers” or “preventers”), which are to be taken on a regular daily basis to reduce underlying airway inflammation and prevent exacerbations. When taken properly, inhaled corticosteroids reduce the likelihood of asthma hospitalization (Blais, Ernst, Boivin, & Suissa, 1998; Donahue et al., 1997). These medications have become an integral part of asthma management, and their use in children has risen during the past decade (Ernst, Fitzgerald, & Spier, 1996; Goodman, Lozano, Stukel, Chang, & Hecht, 1999). However, there is evidence that not all children who require inhaled corticosteroids receive them (Erzen et al., 1997; Kozyrskyj, Mustard, & Simons, 2003; Mielck, Reitmeir, & Wjst, 1996). Low-income children in particular are more likely to have greater asthma severity and therefore a greater need for inhaled corticosteroids (Eggleston et al., 1998; Finkelstein et al., 2000; Finkelstein, Lozano, Farber, Miroshnik, & Lieu, 2002). In recent years, the cost and complexity of asthma management have grown with the advent of novel treatments such as long-acting β -agonists, leukotriene antagonists, and 5-lipoxygenase inhibitors (Finn et al., 2003; O’Byrne, Israel, & Drazen, 1997).

An important concern is that the treatments most needed for asthma control are among the most costly. For many families, prescription costs are, in large part, paid by employer-sponsored drug benefit plans or plans that are privately purchased. On the other extreme are poor families who qualify for government assistance. However, there are many lower income “working poor” parents whose household incomes exceed the poverty level and the minimum necessary for government assistance and who remain without medication insurance. For these families, the out-of-pocket expenditures required to purchase asthma medications can be a formidable financial barrier. Not surprisingly, uninsured children with asthma have poorer health outcomes and face more health barriers than those with insurance (Wood et al., 2002).

While a number of qualitative studies have investigated parental perceptions regarding their children’s asthma (Englund, Rydstrom, & Norberg, 2001; Jerrett & Costello, 1996; Kieckhefer & Ratcliffe, 2000; Kurnat & Moore, 1999; Lauritzen, 2004; Mansour, Lanphear, & DeWitt, 2000; Ostergaard, 1998; Peterson-Sweeney, McMullen, Yoos, & Kitzman, 2003; Svavarsdottir, McCubbin, & Kane, 2000; Young, Fitch, Dixon-Woods, Lambert, & Brooke, 2002), these studies focused on issues related to the diagnosis, treatment, and management of the child’s condition. No study has specifically explored parental perceptions related to the economic hardship imposed by asthma management in low-income families. The

purpose of this qualitative study was to explore how purchasing children's asthma medications influenced household purchasing behavior, standard of living, and perceived quality of life in low-income families without medication insurance.

METHODS

Study Design

A qualitative descriptive approach (Buston, Parry-Jones, Livingstone, Bogan & Wood, 1998; Sandelowski, 2000) was used to focus on the parental experience of purchasing asthma medications for their children. In-depth interviewing was used to elicit participants' views of their lives as they portray their experiences and observations (Charmaz, 2002).

Study Participants

Subjects were recruited from participants in a larger cohort study examining the impact of drug plan access on health outcomes and use of health services in 879 children with asthma in the Greater Toronto Area. Inclusion criteria for the subgroup were defined to represent a low-income sample, with household incomes not exceeding approximately twice the U.S. 2003 federal poverty level (DeNavas-Walt, Proctor, & Mills, 2004). Inclusion criteria were: (a) children aged 1 to 18 years with clinically diagnosed asthma, (b) use of asthma medication in the last year, (c) household income less than U.S. \$45,000 per annum, and (d) no drug plan. Although families may have had more than one child with asthma, only a single eligible child from any family was enrolled. Of 45 eligible parents, 10 could not be reached, 9 declined to participate, and 26 consented verbally by telephone. Interviews were scheduled with 21 parents and were successfully completed with 17 parents. Interviews were conducted in their homes between June 2002 and February 2003. The study was approved by the institutional Research Ethics Board, and all parents provided informed consent.

Data Collection

Before each interview, responses to structured questionnaires on demographics, socioeconomic status, medical history, medication use, health services use, and asthma-specific health-related quality of life (Juniper et al., 1996) that were collected in the larger study were reviewed by the interviewer. This process allowed the interviewer to gain an understanding of the participants' backgrounds.

The research questions of interest included: Where does payment for children's asthma medications fit within families' day-to-day priorities? Do families make adjustments in their standard of living as result of having to purchase asthma medications? What are these adjustments (i.e., sacrifices or reductions), and how do they affect quality of life? What strategies related to medication use (e.g., reducing dosage) are used to cope with the cost and help limit the negative impact on standard of living? These questions informed the development of a interview topic guide. This guide was supplemented by a review of the relevant literature as well as a review of questionnaires used in studies that explored the economic impact of health care resource use. The guide focused initially on the following topics: (a) types of prescribed drugs, cost, and cost versus effectiveness; (b) prescription acquisition, drug administration, and alternative treatment strategies; (c) effects of

medication purchasing on the family; and (d) possible payment assistance. Interviewees were encouraged to discuss how they managed to purchase medications for their child's asthma in the context of everyday life. Questions about effects on quality of life allowed parents to express their personal perceptions and understanding of quality of life in the family and household without imposing a structured definition. Face and content validity of the interview topic guide were assessed by the co-investigators.

The in-home interviews lasted 30 to 90 minutes. During the interviews, the researcher checked that his understanding of the parents' accounts was valid by "reflecting back" or summarizing what he had been told to see if the interviewee concurred. If necessary, further questions were asked to ensure that the respondent's point of view had been fully explored. Interviews were audiotaped and transcribed verbatim. In addition, researcher field notes were taken before and after the interviews to record thoughts and observations pertaining to the study. Based on a review of the tapes, notes, and the first 10 transcripts, it was recognized that saturation of themes was achieved, that is, no new concepts were being expressed. After listening to the audiotapes of all the participants, it was judged that transcription of subsequent interviews would not provide additional insight.

In all interviews, the mothers were present as the primary caregiver, and in five cases, spouses participated. The children with asthma were introduced to the interviewer in most sessions; however, no children were present during the interviews.

Analysis

Audio transcripts were reviewed for accuracy. Analysis occurred concurrently with data collection to ensure iterative immersion in the data. Thematic analysis was applied to the data recorded in the transcripts and field notes. Multiple readings and reflections on each transcribed interview allowed for an understanding of each participant's account and determination of the context. Following the first few interviews, the transcripts were compared to identify similarities and differences in terms of content. The text was blocked to track specific topical areas and to assist in the identification of themes and relationships in content. These blocked areas of text reflected the main areas of interest within the interview guide in addition to new themes that emerged from the data. This procedure was repeated as more interviews became available. The emerging concepts were arranged into categories. A theme code book was developed wherein specific codes were named and defined. This code book was then used to systematically code all transcripts. When no new categories or themes were identified and theoretic saturation was reached, the analysis was concluded.

RESULTS

Sample Characteristics

Parent characteristics are displayed in Table 1. Approximately half the sample was immigrants to Canada and originated from Europe (2), Carribean/West Indies (4), and Asia (2). Although reasonably well educated, 30% were at or below poverty level. Child characteristics in the sample are compared with the original cohort in Table 2. The age of children and exposure to second-hand smoke were comparable to the larger sample.

Although the proportion of boys was higher in the study sample, it remains consistent with surveys that demonstrate a higher prevalence of asthma in boys (Burr, 1993; Lava et al., 1997; Millar, 1998). The children in this low-income group demonstrated greater asthma severity as evidenced by higher rates of asthma attacks, urgent health care visits, and school absences. The higher number of concomitant asthma medications may reflect this greater asthma severity. Fifteen percent fewer respondents in the low-income group reported their child's health as "excellent" or "very good" compared with the original cohort.

Fifty-two prescriptions for asthma medications were reported among the 17 respondents (Table 3). All children had a prescription for an inhaled corticosteroid, and a bronchodilator also was prescribed for 16 of 17. Interestingly, 17 of 22 prescriptions (77%) for bronchodilators were generic drugs, whereas all of the prescriptions for inhaled corticosteroids were for more expensive brand-name medications. Three children were receiving one of the newer agents, such as a combination drug (long-acting β -agonist plus inhaled corticosteroid) or a leukotriene antagonist. Only five of the prescriptions, all brand-name medications, were obtained free of charge from a physician or clinic.

The six themes that emerged from the qualitative analysis are presented in the Box. Each theme is discussed in detail.

BOX

Emergent themes

- Costly asthma prescriptions and one-time expenses
- Value for money
- Lack of choice and lack of help
- Asthma drug purchasing priority and following the prescription
- Doing without means standard of living is affected
- Potential payment assistance schemes

Costly Asthma Prescriptions and One-time Expenses

Although parents believed the prescribed asthma medications were expensive, they understood and accepted the importance of maintaining a proper asthma medication regimen. The parents seemed reasonably well informed as to the function of each drug in terms of whether the drug helped immediately to "relieve" the pulmonary bronchoconstriction (e.g., salbutamol) or helped "control" asthma by treating the inflammation in the lungs (e.g., budesonide). In all cases, a brand name or generic version of salbutamol was used alongside an anti-inflammatory. Most parents reported that at one time, they had used or were currently using a nebulizer. In nearly all cases, asthma-related education had been provided at asthma clinics.

Annual out-of-pocket expenses ranged from approximately U.S. \$300 to U.S. \$3000 per annum. The maximum was reported in a family with three children with asthma: "We've

always dealt with the XY drugstore and when my husband went through that recession thing, of course the place he was at weren't paying their drug plan, so we ended up owing the pharmacy, like, \$1500 bucks through all this."

In addition to prescription costs, most respondents made one-time investments such as nebulizers, spacers, air purifiers/conditioners, and nonallergic linens. Home renovations, wood floor installation, and duct cleaning also were common. Many respondents had plans to purchase equipment or make recommended renovations when they would have funds available.

Value for Money

Given that these drugs were necessary and perceived to be the "only option," parents believed that the monthly asthma drug expenditure was "money well spent" and represented good value: "I'd pay anything for him to be comfortable . . . to say that I'm not getting value for my money, I mean, of course I'm getting value for my money because it's helping him with his asthma . . . it is doing the job, but it is pricey." "I think a kid's medication is more important than your own interests, right?"

In addition, these medications were perceived to provide good value because they allowed parents to cope with their child's asthma at home. The parents understood that if they did not have access to the drugs they would have to go to the doctor, hospital, or walk-in clinic to deal with asthma attacks and incur other costs, such as school absenteeism, lost time at work, payment for baby sitters, or imposing on friends for child care support. Even with proper at-home medication management, it was recognized that exacerbations could still occur that would result in the aforementioned costs.

Lack of Choice and Lack of Help

Respondents believed that they had no choice but to pay for the drugs or their children would suffer. Parents expressed a sense of helplessness regarding getting financial help to cover drug costs: "There's totally no choice involved. If you have a child you have to get that medication whether you have to rob a bank to do so. You have to get that medication."

Although in a few cases doctors provided sample drugs, interviewees did not believe doctors are responsible for providing drug cost relief. It was generally considered inappropriate to discuss personal financial problems related to drug payment because respondents believed doctors could do little to help them. Although some parents turned to relatives and friends for temporary loans to cover asthma medication costs, most were reluctant to consider this type of help. Rarely was the issue of having to pay for prescriptions drugs raised with friends or relatives.

Asthma Drug Purchasing Priority and Following the Prescription

In nearly every interview, given limits on available monthly funds, the purchase of asthma medications superseded the purchase of other prescribed drugs or health products for other family members. Visits to doctors were delayed, knowing they would likely result in a prescription, or the purchase of other prescribed medications were deferred until they were

affordable. The purchase of nonprescription medications also were often delayed or never made. For some persons, purchasing asthma medications for their asthmatic child took precedence over buying that same child new eyeglasses.

Purchasing the number of prescribed asthma medications or refills as directed by their physicians was the usual course of action, and parents usually followed dosage recommendations. After the first large payout for multiple prescriptions as well as a nebulizer or spacer if needed, the need for further large expenditures was reduced because the prescriptions did not run out together. A few parents indicated that when they were short of funds and two prescriptions were needed, they would purchase only one of the two prescribed medications. Contrary to treatment guidelines that emphasize the importance of chronic use with an inhaled corticosteroid (“controller”) (Ernst et al., 1996), when faced with a choice, a cheap generic version of salbutamol, a short-acting β -agonist bronchodilator (“reliever”), usually was selected because of its ability to provide immediate relief during a mild or more severe attack. As soon as possible, the second, anti-inflammatory medication would be purchased: “Sometimes I buy Ventolin only because the money’s short . . . it helps the most immediately.”

In rare instances, respondents admitted that they stretched out dosages, knowing that in the short term they could not afford to refill the prescription. Most family members were aware of generic brands as a less-expensive option.

Doing Without Means Standard of Living Is Affected

A common theme identified by all parents was the negative impact on their standard of living compared with families with drug plans. Parents reported being stretched financially each month because of asthma medication purchases. To afford the asthma medications, purchase of essential items such as clothing and children’s shoes were delayed. Parents reported buying less expensive food and rarely could afford treats. Household, appliance, and automotive repairs were delayed. In some cases, the quality of housing was less than desired because of the need to settle for a lower rent dwelling.

The inability to afford nonessential items or to make financial investments also was perceived to negatively affect standard of living. Few parents stated that they had sufficient money to take family vacations or to go on family outings. A number of parents reported being unable to afford fees for community recreation programs for their children, including their other children who did not have asthma: “Sometimes I didn’t buy my clothes . . . I’ve done without personally. . . .” “I can’t afford to get anything that isn’t absolutely necessary . . . we haven’t been able to get his eyeglasses because we haven’t got the money . . . he’s wearing his old glasses right now . . . because I have not been able to replace them. . . . no birthday presents . . . holes in socks . . . no piano lessons . . . no money to help our daughter with university . . . no holidays.”

While the list of essential and nonessential sacrifices was varied and extensive, respondents appeared to be coping with these daily issues. However, in addition to living under the financial constraints that affected daily choices, they also were unable to plan and save for

important longer term investments such the child's future education, retirement, and a larger home.

Potential Payment Assistance Schemes

Interviewees believed that government programs should pay for at least a portion of their drug costs. In nearly all cases, parents were willing to pay a portion of the costs or an annual fee: "I would like the government to supply medication for everyone . . . especially the ones who need it." "I'd like to see more of a specialized clinic where you could walk in and have asthma banks and services . . . medication should never be held back from people (who cannot afford it)."

DISCUSSION

This study demonstrated that the salient negative contributing factors to self-assessed quality of life in the family and home were the inability to cope financially with other family health-related problems, the need to make sacrifices in purchases of essential and nonessential household items, and the inability to save money for longer term, priority investments that could improve the family's situation in the future. A family's standard of living in the context of this study was defined by how well the family lives at home day to day, by lifestyle decisions, by how much the family enjoys regular family activities inside and outside the home, and importantly, by the capability to achieve financial security in the longer term. The results of this study suggest that the standard of living of low-income families with high out-of-pocket asthma medication expenditures is diminished.

Disruptions to standards of living and lifestyle decisions in families with children with chronic disease have been observed by others. Kurnat and Moore (1999) observed that the cost of managing asthma can be overwhelming and a major source of stress to the family without adequate health insurance for medications (Kurnat & Moore). In interviews with parents of children with asthma, more than half reported concern about the lack of money available for "extra pleasures." Kurnat and Moore advocated that health providers inquire about insurance coverage and refer families to social services when necessary to help them cope with the financial burden. Beresford (1994) acknowledged the negative impact on financial resources associated with caring for a child with a chronic illness, and several researchers have observed that parents (Beresford; Englund et al., 2001) as well as the children (Gabe, Bury, & Ramsay, 2002) may feel emotionally and socially isolated. In the focus group study by Mansour et al. (2000) of parents of asthmatic children, parents reported that cost was a deterrent to purchasing their child's asthma medications and found that changes to the home environment, such as purchasing air conditioners and replacing carpeting, was too expensive. As found in the present study, these parents reported that the constraints placed on them because of their child's asthma diminished their own quality of life.

In interviewing parents of children with asthma, several researchers have found that a child's asthma placed restrictions and demands on the family as a whole (Englund et al., 2001; Jerrett & Costello, 1996; Kurnat & Moore, 1999), requiring a reorganization of daily activities and changes to household rules (Jerrett & Costello). The need to change and adapt

to a household containing one or more children with asthma was itself a source of stress, particularly when the changes conflicted with existing lifestyles or limited family activities, as was found in this study.

The distress expressed by parents may be multifactorial. Several studies have documented parental anxiety that related to insufficient knowledge of the disease, to fear of the child suffering or dying, as well as to the physical and financial responsibilities of providing care for an asthmatic child (Jerrett & Costello, 1996). High parental stress levels were associated with increased use of emergency services and hospital admissions (Wood et al., 2002). An important component of any asthma management plan is addressing the various sources of anxiety.

Most parents in the present study had received some sort of asthma education and reported that they followed dosage recommendations. The fact that some parents reported preferring the cheaper β -agonist over the more expensive inhaled corticosteroid when forced to make a choice because of limited funds is a concern because it violates current asthma management guidelines that place a priority on reducing airway inflammation with inhaled corticosteroids (Ernst et al., 1996). Whereas generic versions of salbutamol are numerous, only one inhaled corticosteroid, budesonide, is available in a cheap generic formulation in Canada. Thirteen of the children in the study were prescribed brand-name fluticasone, a more potent agent, which comes in several strengths and is considerably more expensive than generic budesonide. The fact that the drugs most needed for asthma control are among the most costly creates a worrisome impediment to adequate asthma management in low-income families. Kolbe (1999) noted that overwhelming socioeconomic factors may nullify the positive influence of asthma education. He further stated that unless financial concerns are addressed, asthma education is unlikely to be beneficial. This study found that parents were reluctant to discuss financial difficulties related to medication purchases with their physicians. This has also been found in adults with chronic disease (Schafheutle, Hassell, Noyce, & Weiss, 2002). A lack of communication about these issues will only further hinder optimal asthma management.

In caring for children with asthma, health care providers, including physicians, nurses, nurse practitioners, asthma educators, and respiratory therapists must consider how a family's socioeconomic status may affect that family's ability to cope with the child's asthma. Building trust and effective communication is essential to allow health care providers to explore reasons for poor compliance and suboptimal asthma management that may relate to economic hardship. Health providers can inquire about insurance coverage and access to needed medications and can refer families to social services when necessary. Challenges related to adapting to the health care system, to the bureaucracy of insurance coverage, and to adhering to an asthma management plan are particularly acute for immigrant families who are often low income with limited verbal and written skills in the language of their new land. Health care providers must ensure that procedures are in place to provide assistance to these and other vulnerable groups.

A number of limitations were encountered in this study. Although the sample size was low, the themes identified in the transcripts were consistent, and saturation of themes was

reached. Whereas these responses may not necessarily be representative of a national sample, the observations regarding parental choices and effects on standard of living and quality of life can be generalized to jurisdictions where segments of the population remain uninsured.

Low-income parents of children with asthma who have no medication insurance benefits face financial hardships that are manifested in a variety of sacrifices in the purchase of essential and nonessential household items. These sacrifices may in turn have deleterious effects on the health of other family members by reducing consumption of other forms of health care and by creating sustained levels of stress and anxiety. Policies that improve access to medications for low-income uninsured families would have a profound and positive impact.

Acknowledgments

This research was funded by an operating grant from the Canadian Institutes of Health Research (Grant No. 37919). Dr. Ungar is supported by a Canadian Institutes of Health Research New Investigator Career award.

We gratefully acknowledge the assistance of Ms. Kelly Sequeira and Ms. Donna Zaza in the conduct of this research. We remain thankful to the parents who volunteered their time to participate.

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TABLE 1

Parent characteristics

Characteristic	Mean (range) or n (%)
Born in Canada	9 (53)
Marital status	
Married/common law	11 (65)
Separated/divorced	3 (18)
Single/widow	3 (18)
Mother's education	
Some secondary school	1 (6)
Completed secondary school	9 (53)
Some college/university	2 (12)
Completed college/university	5 (29)
Number at home	4 (2 to 6)
Mother's employment	
Employed full time	3 (18)
Employed part time	9 (53)
Homemaker	5 (29)
Household income (\$U.S.) *	
Less than or equal to \$7400	2 (12)
\$14,800 to <\$22,200	3 (18)
\$22,200 to <\$29,600	4 (24)
\$29,600 to <\$37,000	4 (24)
\$37,000 to <\$44,400	4 (24)

* These ranges were converted from the following Canadian dollar values used in the original intake questionnaire: less than or equal to \$10,000; \$20,000 to \$29,999; \$30,000 to \$39,000; \$40,000 to \$49,999, \$50,000 to \$59,999.

TABLE 2

Child characteristics

Characteristic	Mean (range) or n (%)	Study sample (n = 17) Original Cohort (n = 879)
Child's sex		
M	13 (76)	542 (61)
F	4 (24)	347 (39)
Child's age (y)	6.8 (2 to 15)	6.9 (<1 to 18)
No. of asthma medications currently used	3.2 (1 to 6)	2.6 (1 to 8)
Asthma attacks in the past 6 mo	4.4 (0 to 15)	3.5 (0 to 50)
Emergency department visits or hospital admissions in the past 6 mo	3.5 (0 to 17)	1.8 (0 to 30)
School absences in past month	2.4 (0 to 10)	1.6 (0 to 30)
Exposure to second-hand smoke	4 (24)	200 (23)
Self-reported health status		
Excellent	2 (12)	103 (12)
Very good	2 (12)	233 (27)
Good	10 (58)	298 (34)
Fair	2 (12)	159 (18)
Poor	2 (12)	77 (9)
Unknown	0 (0)	9 (1)

TABLE 3

Asthma medication use

Medication regimen or type	No. of children	%	No. of prescriptions	%
Medication regimen				
Inhaled corticosteroid alone	1	6		
Bronchodilator with inhaled corticosteroid	10	59		
Bronchodilator with (inhaled corticosteroid or combination drug [*]) and with oral steroid	6	35		
Medication type [†]				
Brand-name bronchodilator			5	10
Generic bronchodilator			17	33
Brand-name inhaled corticosteroid			21	40
Generic inhaled corticosteroid			0	0
Brand-name combination drug [*]			2	4
Oral steroid			6	12
Brand-name leukotriene antagonist			1	2

* Combination drug combines a long-acting β -agonist with an inhaled corticosteroid in a single inhaler.

[†] Based on 52 prescriptions reported in 17 respondents.