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Addressing Cost Barriers to Medications: A Survey of Patients Requesting Financial Assistance

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Financial stress associated with healthcare imposes a substantial burden on US families, including a high rate of cost-related nonadherence to prescription medications.¹⁻⁸ For example, 20% of seniors in fair or poor health report cost-related nonadherence despite a high rate of Medicare prescription drug coverage.⁹ Cost-related nonadherence leads to higher rates of morbidity and mortality, including elevated rates of cardiovascular events.^{10,11}

A number of factors suggest that cost barriers will continue to increase. First, despite a recent slowdown, the rate of growth of healthcare costs continues to exceed that of economic growth.^{12,13} Second, high-deductible health plans, which were further stimulated by the creation of tax-advantaged health savings accounts through the Medicare Modernization Act a decade ago, are growing rapidly, with 19% of workers with employer-sponsored insurance now enrolled.¹⁴ Third, although the Affordable Care Act will significantly expand insurance coverage, the minimum coverage requirements will still permit a high level of cost sharing.¹⁵ As cost barriers grow, patients will increasingly need assistance in making healthcare decisions that involve trade-offs between the efficacy and affordability of treatment regimens. (We will refer to these decisions as cost-efficacy trade-offs.)

Prior studies have examined attitudes and behaviors regarding physician-patient cost discussions. Those studies showed that patients wanted to discuss costs with their physician and would invite discussions about affordability.¹⁶⁻¹⁸ However, just 35% of patients experiencing cost-related nonadherence reported having had a cost discussion with their doctor.¹⁷ Although physicians report that cost discussions are important, they often do not recognize when their own patients are experiencing cost barriers.^{16,19} Physicians also perceive that they lack the knowledge to discuss treatment costs, and that time pressures of an office visit prohibit meaningful discussions.²⁰ Given the infrequency of cost discussions, several experts have proposed deploying other members of healthcare teams to screen for financial stress and

potentially intervene.²¹ However, we are not aware of any studies that have tested the acceptability among patients of screening or interventions outside of traditional physician-patient face-to-face encounters.

As cost barriers become more prevalent and start to be recognized, it is important to understand how physicians and patients should incorporate financial considerations into medical decisions. The literature on patient preferences for their own role in medical decision making shows heterogeneous preferences.²² In a national survey,²² the majority of patients reported that they wanted to be asked their opinions on therapeutic options and be offered choices, yet almost half preferred to rely exclusively on their physician's knowledge to acquire information, and just over half preferred to still leave final decisions to their physician. To our knowledge, studies have not examined patients' preferences regarding physicians' roles in navigating cost-efficacy trade-offs.

In this study, we had 2 main objectives. First, in a sample of patients with a chronic disease, we evaluated comfort with being screened for medication cost-related barriers by different types of healthcare providers and through different methods. Second, we examined patients' preferences for physician and patient roles in making medical decisions involving cost-efficacy trade-offs.

METHODS

We conducted a mail survey of a random sample of adults with a chronic disease who had applied for financial support to the HealthWell Foundation, a national nonprofit organization that assists patients with co-payments, co-insurance, and health insurance premiums (www.healthwellfoundation.org); both individual and corporate donors contribute to the HealthWell Foundation. Embedded in the mailed survey was a randomized experiment to evaluate patient preferences regarding physician approaches to helping patients navigate cost-efficacy trade-offs in the prescribing of medications. The University of Pennsylvania Institutional Review Board approved this study, which was funded by the HealthWell Foundation.

Survey Instrument

We asked participants to rate their level of comfort with their own doctor and other members of the healthcare team screening them for medication cost-related barriers to care. In addition to their own doctor, we asked about nurses, professional counselors, and trained volunteers at their doctor's office, as well as pharmacists where they fill prescriptions. We also asked participants to rate their comfort with a range of strategies outside the normal doctor-patient visit, to screen for cost-related nonadherence or cost-barriers. These strategies included "having someone from your doctor's office review your records to see how often you fill your prescriptions"; "having your insurance company review your records to see

how often you fill your prescriptions”; “having your pharmacy review your records to see how often you fill your prescriptions”; “filling out a form in your doctor’s office”; and “responding to an email message from your doctor’s office.” Participants rated their level of comfort with each item in this section on a 1-to-10 scale where 1 was very uncomfortable and 10, very comfortable.

The next section of the survey included an embedded experiment in which participants were randomized to 1 of 3 versions of a vignette describing a clinical decision with cost-efficacy trade-offs. Every survey included the following: “Lucy has high cholesterol. She can take a medicine to help prevent a heart attack. The options are Medicine A and Medicine B. Medicine A costs Lucy \$20 a month. It works fairly well. 80 out of 100 people get better. Medicine B costs Lucy \$100 a month. It works very well. 99 out of 100 people get better.” The experimental conditions varied as follows, with one-third of the survey sample allocated at random to each condition; in condition 1, the “cost-conscious” decision style, Dr Thomas is aware that Lucy is having difficulty paying for her medications and makes a unilateral decision to prescribe Medicine A—the less expensive, less effective medication. In condition 2, the “cost-indifferent” decision style, Dr Thomas knows that Lucy is having difficulty paying for her medicine but unilaterally decides to prescribe Medicine B because it is “best.” In condition 3, the “patient-directed” style, Dr Thomas knows Lucy is having trouble paying for her medicines. Before Dr Thomas prescribes a medicine, she discusses Medicines A and B with Lucy and lets Lucy decide. Participants rated their level of comfort with the decision style depicted in the condition to which they were randomized on a 1-to-10 scale, where 1 was very uncomfortable and 10, very comfortable.

We also asked respondents about their experiences with cost-related nonadherence or difficulty paying for their medications in the last year, as well as whether they would like to discuss costs with their doctor. Self-rated health was measured using the SF-1 questionnaire, a predictor of all-cause mortality.²³ Physician trust was measured using a 5-item instrument.²⁴ The HealthWell Foundation provided demographic information for participants, including income, age, insurance status, and marital status.

Survey Administration

We administered the survey between August 2012 and October 2012. We mailed surveys to 1400 individuals randomly selected from the HealthWell Foundation database. We sent each individual an introductory letter, followed approximately 5 days later by the mailed survey and consent form as well as a \$5 participation incentive. We followed this mailing with a postcard reminder 1 week later, and a fourth and final mailing containing a second survey approximately 2 weeks after that. Among the people invited to participate, 107 were unreachable because of incorrect addresses; and 6 people were deceased according to a family member. A total of 842 participants responded for a final survey response rate of 60.4%.

Statistical Analysis

Our main outcomes were how comfortable the respondent was with the method or decision described in the survey instrument. We dichotomized our outcome into high comfort (8 to 10) versus low to medium comfort (1 to 7). We tested bivariate associations between demographic characteristics, self-reported health status, self-reported cost difficulty, and self-reported cost-related nonadherence with our main outcomes using χ^2 statistics. We also tested for differences between our 3 experimental groups using χ^2 statistics. We adjusted for characteristics that differed ($P < .10$) between experimental groups using logistic regression. We performed all analyses using the Stata software program, version 12.1 (StataCorpLP, College Station, Texas).

RESULTS

In this sample of adults with a chronic disease who faced financial challenges associated with their healthcare, the majority were women and almost half were 65 years or older (**Table 1**). Although 70% of the sample earned less than \$30,000 per year, most respondents had some form of health insurance—either through a private insurer or through Medicare. More than half of the respondents rated their health as fair or poor. The majority of participants noted that they had experienced difficulty paying for prescriptions and/or cost-related medication nonadherence in the past year. Most agreed that, “I want my doctor to think about cost when choosing a medicine for me” (86%). Among the 1400 people mailed a survey, responders were somewhat older than nonresponders ($P = .05$), but had similar income ($P = .36$) and insurance coverage ($P = .20$) (**eAppendix A**).

Financial Screening by Healthcare Team Members

Participants were asked how comfortable they would be with different members of the healthcare team inquiring about their own financial challenges (**Table 2**). Responses suggest that patients view members of the healthcare team differently. Participants most often reported being highly comfortable being questioned by physicians (81.1%), followed closely by pharmacists (74.8%). Nurses (69.4%) and professional counselors (68.3%) ranked next in terms of participants' comfort, with trained volunteers (50.5%) least often endorsed. These ratings were similar across all sociodemographic groups. Participants who reported a high degree of physician trust reported higher levels of comfort with all members of the healthcare team.

Financial Screening Tools

Participants were prompted that “there are many ways your doctor can learn that you are having trouble paying for your medicines” and were asked about their comfort with a range of screening strategies to identify patients' financial challenges (**Table 3**). The majority of participants reported that they were

highly comfortable with record reviews by doctors' offices (58.8%), insurance companies (53.3%), and pharmacies (62.1%), as well as with self-reported screening paper work to be completed in doctors' offices (62.2%). However, participants were significantly less likely to report that they were highly comfortable with the use of email from the doctor's office as a screening tool (48.1%).

The proportion of people reporting a high level of comfort with each screening strategy did not vary by sex, age, marital status, income, insurance status, or health status. However, there were significant differences between participants who did and did not report difficulty paying for their prescriptions (Table 3). Participants who reported difficulty paying (vs no difficulty) were open to a range of strategies. They were significantly more likely to be highly comfortable with screening by doctor's office or pharmacy record review, in-office paper-based screening, and screening via e-mail. Higher trust in physicians was also significantly and positively correlated with endorsement of every proposed approach to screening for financial difficulty (Table 3).

Preferred Patient-Physician Roles in Cost-Based Decisions

Experimental vignettes were used to model a clinical scenario in which a patient could be treated with a higher- or lower-priced cholesterol-lowering medicine; in each scenario, the higher-priced medicine was more effective. Participants were randomly assigned to 1 of 3 conditions—in all 3 conditions, the doctor is aware that the patient was having financial difficulty. In the first condition, the “cost-conscious” doctor unilaterally chose a lower-priced, marginally less effective medication. In the second condition, the “cost-indifferent” doctor chose the higher-priced medication because it was the most effective. In the third scenario, the doctor and patient discussed the cost-efficacy trade-offs and the ultimate decision was “patient-directed.” This last scenario was significantly favored. In unadjusted analyses (**Table 4**), the majority (57.6%) of participants assigned to the patient-directed condition reported that they would be highly comfortable (>7 on 1-10 scale) with a clinical decision style like this in which the patient ultimately chose which medication to use. A lower proportion of patients reported that they would be highly comfortable with the other clinical decision styles. Only 32.5% of participants reported that they were highly comfortable with the cost-indifferent style in which the physician unilaterally chose the more expensive, marginally more effective medication. Even fewer participants (25.2%) were highly comfortable with the cost-conscious decision, in which the physician unilaterally decided to prescribe the less expensive, marginally less effective medication.

In multivariate analyses (Table 4) that adjusted for respondent characteristics that varied ($P < .10$) between experimental groups (health status and marital status), participants' ratings of comfort differed significantly across experimentally assigned clinical decision styles. Compared with participants who were randomized to the cost-conscious decision style, in which the physician unilaterally chose the

lower-cost medication, participants randomized to the patient-directed condition were substantially more likely to report a high level of comfort with the clinical decision style (odds ratio [OR], 4.64; 95% CI, 3.14-6.84; $P < .001$). A high level of comfort was more common (OR, 1.53; 95% CI, 1.04-2.24; $P = .03$) among participants assigned to the cost-indifferent condition (physician chose the higher-price medicine because it was “better”) than among participants assigned to the cost-conscious condition (physician chose the lower-price, marginally less effective medication). Results were similar when also adjusting for age.

Following the rating of the vignette, all participants were asked to rate, on the same 10-point Likert scale, their comfort with the same vignette modified to depict a shared-decision style, in which the doctor and patient collaboratively chose the medication. Most (85%) participants were highly comfortable with that approach. Later in the survey, we asked participants to explicitly choose a preferred physician role if the respondent was “having trouble paying for my medicines.” Respondents favored a shared decision (77%; “my doctor gives me options, tells me their prices and how well they work, and together we decide”) over a patient-directed decision (14%; “my doctor gives me options, tells me their prices and how well they work, and lets me decide”), cost-indifferent decision (6%; “my doctor prescribes the best medicine for me, even if it is more expensive”), or cost-conscious decision (3%; “my doctor chooses a cheaper medicine, even if it is not the best”).

DISCUSSION

Participants in our study articulated their preferences around screening and negotiation of cost barriers in their medical care. The most important finding from this work is that participants were open to having their physicians engage them in discussions regarding medical decision making when faced with difficulty paying for prescription medications. Participants were also open to such discussions with pharmacists, nurses, and other members of the healthcare team—though less so with lay health workers. The second important finding is that patients want a participatory decision-making process to navigate cost-efficacy trade-offs and do not want to defer those decisions to their doctor. This research has several important implications for clinical practice and future research.

First, as more patients enroll in health plans that require high levels of cost sharing, it will be important for providers to monitor for, and pre-empt when possible, cost-related nonadherence. Prior studies show that physicians often do not recognize when their patients are experiencing cost barriers. To identify cost barriers to medication adherence, participants in this study were asked if they were comfortable with a range of screening strategies using administrative records or queries in the doctor’s office. Our study points to alternative personnel and approaches that medical offices could utilize, with likely broad patient support, to better identify patients experiencing cost barriers.

Second, pharmacists are a potential untapped resource and partner for medical practices to engage for cost discussions with their patients. Of all the providers we asked participants about, pharmacists were the only professional group not typically located within medical practices. This presents both barriers and opportunities. On the other hand, communication between medical offices and pharmacists can be a greater challenge given the separation of electronic communication systems. On the other hand, at least for medications, pharmacists have ready access to cost information, and likely have frequent contact with patients given the need for medication refills, and may be in closer geographic proximity to a patient's home and have more flexible access. Further research is needed to determine how pharmacists can be effectively deployed to lead cost discussions with patients and how these discussions compare with those between patients and physicians.

Third, patients want to engage with their physicians in discussions and decisions regarding trade-offs between the costs and efficacy of their medications. The finding that patients want to engage in shared decision making is not new.^{25,26} Our study adds to the literature by showing that patients also value shared decision making when facing cost-efficacy trade-offs due to personal financial barriers. Physicians engaging in shared decision making when confronting cost-efficacy trade-offs, face a number of challenges, including time and knowledge of costs. These challenges point to the need to develop and deploy new decision-making tools (eg, tools within electronic medical records), as well as training within medical education and practices, to help patients navigate these decisions.

Limitations

Our study has several limitations. First, our participants were all applicants to a patient assistance foundation and tended to be older, insured, and female. These participants, given their applications to a patient assistance foundation, might have different attitudes than other individuals about seeking help or discussing personal financial matters with healthcare providers. In addition, they may have greater levels of patient activation or may just have different strategies for dealing with personal adversity than other members of the population. We also did not have measures of race and ethnicity. Thus, our study may overestimate patient willingness to discuss cost barriers with healthcare providers or patient desire to engage in participatory decision making around cost-efficacy trade-offs. However, by recruiting participants from this program, we were able to readily identify individuals with a chronic condition facing cost barriers.

Second, we measured attitudes toward different physician decision roles using experimental vignettes. Patients' expressed preferences in these hypothetical scenarios may differ from their behaviors in actual clinical encounters. However, the experimental design increases our confidence that the differences we

observed across experimental groups are likely to reflect between-group differences that would manifest in clinical encounters. Third, we anticipate that patients would view physician roles in cost-efficacy trade-offs differently depending on the clinical conditions or types of treatment under consideration. This question was beyond the scope of our study.

Fourth, as with all survey research, it's possible that responders and nonresponders have differing attitudes. However, while it does not eliminate the concern for nonresponse bias, our relatively high response rate of 60.4% further mitigates it.

CONCLUSIONS

Given the underlying trends in costs and insurance design, more patients are likely to confront cost barriers. Patients desire more direct communication with healthcare providers regarding cost-efficacy trade-offs; they want to be included in the decision-making process. Interventions will have to address 2 major barriers to effective communication regarding cost-efficacy trade-offs. First, healthcare providers receive little to no formal education in discussing patients' financial challenges and implications for health, health behaviors, and treatment compliance. Second, the costs of healthcare, including anticipated out-of-pocket costs for patients, are not at all transparent to providers or patients. Corrective action is needed on both fronts in order to deploy screening and intervention strategies in clinics, hospitals, and pharmacies.

Acknowledgments

The authors thank the HealthWell Foundation for support of this research. This work was presented as an oral presentation at the Society of General Internal Medicine Annual Meeting on April 26, 2013, in Denver, Colorado.