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Research and Applications

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"It's a mess sometimes": patient perspectives on provider responses to healthcare costs, and how informatics interventions can help support cost-sensitive care decisions

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Objective: We investigated patient experiences with medication- and test-related cost conversations with healthcare providers to identify their preferences for future informatics tools to facilitate cost-sensitive care decisions.

Materials and Methods: We conducted 18 semistructured interviews with diverse patients (ages 24–81) in a Midwestern health system in the United States. We identified themes through 2 rounds of qualitative coding.

Results: Patients believed their providers could help reduce medication-related costs but did not see how providers could influence test-related costs. Patients viewed cost conversations about medications as beneficial when providers could adjust medical recommendations or provide resources. However, cost conversations did not always occur when patients felt they were needed. Consequently, patients faced a "cascade of work" to address affordability challenges. To prevent this, collaborative informatics tools could facilitate cost conversations and shared decision-making by providing information about a patient's financial constraints, enabling comparisons of medication/testing options, and addressing transportation logistics to facilitate patient follow-through.

Discussion: Like providers, patients want informatics tools that address patient out-of-pocket costs. They want to discuss healthcare costs to reduce the frequency of unaffordable costs and obtain proactive assistance. Informatics interventions could minimize the cascade of patient work through shared decision-making and preventative actions. Such tools might integrate information about efficacy, costs, and side effects to support decisions, present patient decision aids, facilitate coordination among healthcare units, and eventually improve patient outcomes.

Conclusion: To prevent a burdensome cascade of work for patients, informatics tools could be designed to support cost conversations and decisions between patients and providers.

Key words: shared decision making, drug costs, test costs, help seeking behavior, insurance, health

INTRODUCTION

Overall healthcare costs in the United States continue to rise; moreover, healthcare spending in the United States was nearly twice that in 10 other high-income countries in 2016.[1] Although healthcare utilization is similar to that in other high-income countries, the cost and frequency of laboratory tests are increasing,[2] and the US ranks highest in per-capita prescription drug spending.[1] Prescriptions account for 17% of spending on goods and services; this is expected to grow nearly 6.3% annually until 2026.[3] Decision making on insurance plans has become especially challenging for consumers with low health insurance literacy and numeracy skills, or those with chronic conditions that require detailed comparisons on affordability and accuracy.[4–6]

Patients' out-of-pocket expenditures have grown steadily since 1970, to $1240 per capita on average in 2019.[7] Out-of-pocket spending grew 4.6% in 2019 to $406.5 billion.[8] Patients express significant concerns about out-of-pocket costs.[9,10] A 2019 survey shows that 26% of US adults said they or a household member had problems paying medical bills in the past year; about half of this group said the bills had a major impact on their family.[11] Moreover, patients do not always know their healthcare costs in advance; 18% of US adults were surprised by a medical bill in the past 2 years.[12]

Previous research suggests the importance of patient involvement in cost conversations related to medication prescribing to avoid negative consequences. For example, high out-of-pocket costs—presumably not discussed in advance—have been associated with more frequent prescription abandonment at the pharmacy,[13] especially among patients with chronic illnesses such as diabetes and hypertension.[14,15] Medication nonadherence due to high costs can negatively impact health and presents a challenge for people with such conditions.[16] A lack of cost conversations may contribute to the high prevalence (41.3%) of multiple pharmacy use (ie, price shopping).[17] Multiple pharmacy use can make it difficult for pharmacists to check drug–drug interactions[18,19] and often does not reduce costs.[20] Unaffordable prescriptions can also lead to pharmacy callbacks, usage delays,[20,21] and financial burdens. Thus, it is crucial to facilitate cost conversations and make cost-sensitive healthcare decisions.

Despite their importance, cost conversations do not always occur.[22] Fewer than 20% of patients reported cost conversations with their physicians regarding recent prescriptions.[23] Similarly, in 2 different studies, 14%[24] and 15%[25] reported that they had talked with their doctor about their out-of-pocket costs before receiving a test, treatment, or medication. Patients have reported feeling that their physicians may not initiate cost conversations due to insufficient time (13%) and/or a lack of solutions (19%).[26] Although price transparency tools are becoming more available and widely used,[3] prescribers still do not always know the actual costs of drugs or medical tests, or their patient's insurance formularies and out-of-pocket costs.[27–29] Providing prescribers with access to formulary and drug cost data influences total drug cost but is not associated with lower out-of-pocket costs; thus, tools are needed to help reduce patients' financial burdens.

Providers may expect that patients will discuss cost concerns. In a study of 151 patient-oncologist conversations, patients started over 70% of cost-related discussions.[30] Providers may not initiate cost conversations due to an ethical ideal that cost should not influence medical decisions.[9] However, financial burdens from out-of-pocket healthcare costs are increasingly being framed as a "side effect" of care, and a source of "financial toxicity" that may impair patients' well-being.[31,32] Scholars argue that believing patients should make decisions based on medical needs and not financial concerns is paternalistic and unjustified.[9]

Patients may also avoid discussing cost and financial concerns due to emotional barriers such as discomfort or embarrassment,[33] or concerns that clinicians either do not know the cost of medications or tests,[32] or lack time or ability to help.[26] Yet, understanding costs in advance may alter patients' treatment decisions.[34,35] Studies have shown that a majority of patients with chronic illnesses,[23] particularly diabetes,[36] may consider inconvenient medication regimens (ie, higher dosing and generic alternatives) to reduce costs. Wu et al[37] found that patients most often choose lower-price testing facilities when informed about alternatives. Supporting this, previous research shows that patients want more cost details in advance during clinical encounters. Henrikson et al[38] found that 92% wanted to know expected out-of-pocket costs before treatment, 81% wanted to discuss costs with their doctor, and 76% expressed comfort in doing so. Thus, patients are open to incorporating cost information into healthcare decision-making,[32,39] and it is important to understand patient perspectives on taking cost into account in care-related decisions.

When known, information about costs and insurance significantly influences physicians' prescribing[40–42] and test-ordering behaviors[43] to reduce patient costs.[44] Price transparency tools have been developed to improve providers' understanding of real-time costs. Early research on these indicates promise to reduce medication spending and test ordering[45–47] and encourage cost-sensitive prescribing.[48]

Less attention has been paid to patient perspectives on informatics tools that might facilitate cost conversations with providers. Barr et al[49] pointed to the potential for interventions to improve shared decision-making (SDM). Informatics tools could address challenges as they promote structure and standardization[50] through prompting and goal setting,[51] and provide a shared reference for discussion during clinical consultations. Patient-facing tools also allow for patient review beyond the limited time with a provider.[52] Indeed, the availability of SDM-focused informatics tools[53,54] and decision aids[55,56] has been shown to impact patient engagement in decision making. A recent study showed that SDM tools used to raise cost questions during the patient–physician consultation triggered cost conversations but did not directly address cost issues or offer solutions.[57] Thus, more study is needed to understand how patients envision informatics tools in initiating and facilitating cost conversations.

Research aims and objectives

We investigated patients' experiences when talking to providers about costs related to medication and tests, as well as general cost barriers; perceptions of appropriate provider and patient roles in cost conversations; and what happens when cost conversations do not occur, and affordability is unaddressed. Further, we investigated, from patients' perspectives, how informatics tools could be designed to facilitate cost conversations and cost-sensitive care decisions.

METHODS

Setting and participants

Participants were recruited from a large Midwestern nonprofit health system with more than 800 physicians and 100 clinics, as well as 11 hospitals. Research team members within the system reviewed medical records to identify outpatients who had been referred to the Population Health department. Population Health referral criteria included value-based contract patients who: (1) had a recent inpatient or emergency department discharge and were risk stratified according to: (a) likelihood of hospital readmission, (b) number of inpatient/emergency department visits in the previous 90 days, and (c) number of medications; or (2) congestive heart failure patients deemed to be at high risk of hospital readmission in the next year per payor data. For nonvalue-based-contract patients, referral criteria included cardiac bundle financing or referrals from health system providers of patients whom they believed could benefit from care coordination. Furthermore, we aimed to develop a diverse sample concerning gender, race/ethnicity, and age. A research team member from the health system (SW) contacted 75 patients via phone to invite them to participate. Team members had no prior relationships with potential interviewees.

Of the 75-patient participant pool, 26 agreed to participate in an interview (34.7%), and 18 completed one (24.0% response rate). Five (6.7%) did not participate after agreeing because they did not answer the interview phone call. Three others (4.0%) decided not to participate when they answered the phone call for the interview. Of the 49 patients (65.3%) who were invited but did not participate, 3 (4.0%) had a previously unknown language barrier not mentioned in the chart, 2 (2.7%) had disconnected telephones, 1 (1.3%) was ill, 17 (22.7%) declined, and 26 (34.7%) did not return the voicemail message. Participants were compensated $40 for their time. Interviews were completed upon reaching data saturation (when later interviews no longer contributed new insights).[58]

Data collection

An interview guide, collaboratively developed alongside health system staff, included open-ended questions and verbal preference-ranking tasks. The interview guide pertained to patients' perceptions of conversations with providers about medication, test costs, and cost barriers, and their thoughts on potential technological interventions to support cost-sensitive care decision-making. The concept of "technological interventions" was first introduced to participants using the following wording: "Imagine that your doctor begins using their computer to help decide between 2 different medication options based on cost and health benefits. How would you feel if your doctor wanted to use this computer tool at your next appointment?"(see Supplementary Appendix A for full Interview Guide). The university's and health system's institutional review boards approved the study.

Semistructured interviews were conducted between August and September 2020 via phone to avoid unnecessary risk due to the COVID-19 pandemic. SW called each interviewee and completed the informed consent process before connecting the patient to BI (main interviewer) and KK for interviews. At the beginning of interviews, participants were asked to verbally complete a brief demographic survey. SW remained on the call to answer patient questions and provide resources in response to social needs disclosed during the call. Interviews typically lasted 1 h; they were audio-taped, transcribed verbatim, and verified by the interviewer.

Data analysis

Using thematic analysis methods,[59] the first author (a doctoral student in Information) read all transcripts to familiarize herself with the data and took notes while developing draft codes. Concurrently, 8 research team members (2 doctoral students, a faculty member in Information, and 5 researchers working full-time in a health system, of whom 2 were clinicians) individually read 7 (~38%) randomly chosen transcripts. They then met several times to discuss patterns and collaboratively develop the codebook. The researchers discussed, negotiated, and reached a consensus regarding codes using an inductive approach.

The first author completed line-by-line coding of transcripts in an initial cycle, using the codebook, while also developing in vivo codes[59] to capture patient perspectives. The first author also used negative case analysis to expand and revise interpretations of individual codes until all outliers were explained.[60,61] In second-cycle coding, initial codes were merged into high-level themes.

Of the 18 interview transcripts, 5 (27.8%) were randomly selected and coded by the first author and third author (a clinical researcher). Interrater reliability was 0.776 for all codes.

RESULTS

Participant characteristics

Of the 18 patients interviewed, the average age was 52.4 (range 24–81; median 49.5); 11 participants (61.1%) identified as female and 7 as male (38.9%), and 38.9% identified as non-Hispanic White. Interviewees accumulated a range of educational experiences, with 4 having a Bachelor's degree or higher (22.2%), 3 having an Associate's degree (16.7%), 3 having attended trade school or some college (16.7%), and 8 having a high-school education or less (44.4%).

Patient experiences of cost conversations with providers

Patients described positive and negative experiences of talking to providers about medication and testing costs and cost barriers. The valence of these experiences was contingent on how well the solution addressed patient challenges and the emotional tenor of the conversation.

On the positive side, patients described providers as either directly providing or connecting them to helpful cost-alleviation resources. In some cases, patients and prescribers addressed costs and cost barriers prior to prescribing decisions; this was not described for tests. Other times, patients in our study worked with providers who did not discuss costs. Table 1 presents evidence supporting these themes.

Receipt of helpful cost-alleviation resources from providers

Perceptions of helpfulness involved providers who provided direct assistance (eg, medication alternatives, samples, or coupons), as compared to those who asked questions about needs (eg, nurses). In these cases, mostly social workers, and sometimes doctors, offered resources that completely addressed the patient's problem. Patients felt supported when offered interest, openness to discussing finances, and proactive assistance.

Providers also referred patients to local organizations, hospital-based assistance programs, and external tools like GoodRx; doctors mainly helped some find lower-cost medications. In these cases, providers connected patients to resources and partially addressed their problem.

Short appointment time presents barrier to cost conversations

Several patients did not experience opportunities to discuss finances. Eight were not asked about financial resources. Two felt that they did not have cost conversations because their appointment was "rushed." Two received pamphlets with referrals. However, only the patient who

Table 1. Patient experiences of cost conversations with providers

Receipt of helpful cost-alleviation resources from providers	“[A social worker] *called me and was asking me: ‘Do you need any financial help?’ That was really good . . . I’m really surprised because they never said anything about financial problems before. And then my family doctor actually contacted her and she called [to provide resources] . . . I was surprised, but feel a lot better . . . [the doctor] will take care of me*” (P9). “*There’s a pharmacist who has discussed [medications] with me . . . openly and she would seek ways to help me by communicating with the doctors to try to find out if there’s another medication . . . that would work or would be less expensive . . . she would even contact the company to see if . . . I could get the medicine cheaper . . . There have been times when [my doctors] provided me with the medicine directly and said ‘here, I’ll pay for it this time for you’* [with a sample] *. . . All my doctors are extremely compassionate people*” (P14). “*It went well . . . when I called to let them know . . . this medication you prescribed, we just can’t afford it; especially with it being a monthly medication. They didn’t hesitate and didn’t have a problem to find . . . something that was a little less expensive for us*” (P1). “[My doctor] *asked me if I needed any help with getting food or financially and then she set me up with a program . . . I was having a hard time with money and trying to put gas in my tank to go to my appointments . . . I think they should have one of the social workers come in and actually talk to the person*” (P10). “*I’ve got a pretty good doctor . . . she listens and talks. It ain’t just a 2-minute visit and bam—you’re out the door. So, I probably could talk to her if I had something pressing*” (P13).
Short appointment time presents barrier to cost conversations	“*Most of the time if you go to the doctor, they rush you in and out*” (P5). “*I try* [to talk about bills] *sometimes, but* [the doctor and nurse] *only see me for like 5 minutes and then they’re gone* . . . [Those interactions have] *been way too short with a lot of them . . .*” (P10). “*It’s difficult because you’ll have to be able to dialogue with them on a level that they will even take the time to listen to. You know, I mean, they’re all rushing and hurrying, and you have to know what you have to say and be able to articulate it right away and . . . concisely*” (P14). “*They kind of just ask you the questions* [about social needs] *in the beginning . . . But it’s just so fast, it don’t even seem like they’re serious about it. So, it’s . . . like, no; no, no, no, I don’t know what you’re talking about, just get these questions over. It doesn’t seem sincere. They’re just questions, they’re not like, ‘Okay if you’re feeling this way you could go do this’ . . . It’s just like, ‘Answer these questions and let’s get this show on the road’ . . . it don’t seem like they care . . . it doesn’t make somebody want to actually open up to them . . . It’s just like a boom, boom, boom, okay let’s move onto the appointment.*” (P17).

received accompanying advice used the resource. Most did not discuss medication costs with prescribers until after filling a prescription or taking a test that was not affordable or not covered by insurance.

Consequences for patients when cost conversations do not occur and affordability is not addressed

A cascade of work follows prescriptions for unaffordable medications and tests

Without cost conversations, affordability issues may surface late in treatment and testing. Overcoming financial barriers required a cascade of work involving many tasks: contacting prescribers to seek a different prescription or medication samples, calling pharmacies to check prices and insurance coverage, contacting insurers to determine coverage, and calling assistance programs, friends, or family to obtain transportation. In some cases, when prescribers could not directly provide assistance, patients in our study were connected with organizations or programs.

When unaffordable medications are prescribed or cost is unknown, patients may make “double trips” to the pharmacy. This occurs when a patient is “shocked” by the cost of an unaffordable, uncovered, or denied prescription. The patient may return to the pharmacy or go elsewhere after making financial arrangements or identifying a lower cost. Some emphasized the embarrassment of trying to find an affordable price.

Without cost conversations, some patients worked to understand the necessity, value, and/or affordability of a prescription or test. This involved asking prescribers about the necessity, contacting billing departments about the feasibility of a payment plan, and contacting various entities to verify insurance coverage. Patients refused tests or medications they deemed unaffordable or inessential (see Table 2).

Material burdens of debt, collections, and payment plans

Patients experienced significant material burdens of healthcare-related debt, collections, and payment plans. Five described needing small monthly payments to afford bills. If payment plans were not offered and they wanted to avoid collections, they paid what they could. Three said they could not obtain relief unless their bills went into collections, so they allowed this. Another mentioned bankruptcy due to bills they had expected insurance to cover. Payment plans could make tests more affordable, but some still faced long-term debt.

Table 2. Consequences for patients when cost conversations do not occur and affordability is not addressed

A cascade of work follows prescriptions for unaffordable medications and tests	"*Sometimes* [with unaffordable prescriptions], *the pharmacy will say the doctor has to call the insurance. The doctor will say … the pharmacy has to call. And then you call insurance and they need to call the doctor. At times … I'd have to call a doctor to … prescribe … a different medication or I'd get on GoodRx …*" (P2). "*I really rely on the pharmacy. I will call and check the prices with the insurance I have … I don't go in there … expecting to pay 20 bucks when it's going to be $100*" (P8). "[I need to know what] *pharmacy covered it, what medicine is covered, and alternatives so I don't have to make double trips … and I don't have to … figure this out alone*" (P18). "*Tests are very expensive … I'm probably the hardest person to deal with because I question why are you doing this test and what exactly is the research on this test and why is [it] so significant? Is it going to … be of value to my whole healthcare? … does it meet my health goals?*" (P14).
Material burdens of debt, collections, and payment plans	"*They send me … a doctor bill … in the mail saying what I owe … if I can't pay it all, I just pay what I can*" (P3). "*Right now, what part the insurance and Medicaid don't pay, I owe the hospital … I'm trying to sign up for financial assistance. I got the paperwork in the mail. I'm going to take it in there … so they can … help me out with it … it's taking a while because I can't write*" (P6). "*I might not be able to afford the deal …* [the billing office] *might know some resources that can help me get some help with this. They might know a program where I can pay monthly, you know …?*" (P7). "*I had to get some bloodwork done … I got a bill and … it was high! And it went to collections because I couldn't afford to pay it when they wanted it, so I just kinda let it go to collections and then I paid it later when I could set up a payment plan at that time*" (P17).
Negative emotional impacts of denied or expensive medications and tests	"*It was devastating, there was nothing I could do—I didn't have no money! There was no way I could pay for that … I had a feeling that I was never going to be able to get this medicine anymore … I've done that with a lot of my other medications also …*" (P5). "*I would say that my healthcare has been a real heavy drag. There are no more trips and … things that we always used to do. We did a lot of travel and a lot of stuff—nothing! Nothing of that kind anymore. It's just pay for the bills for my medical care. Really that's … that's really the life now is just wondering if it's really worth it all*" (P14). "*Sometimes it can be embarrassing to say, 'Hey* [doctor], *I don't have any money.' They bring it up but at least they know so, we can find something to make the payments up*" (P9).
Refusal of medications or postponement of tests	"*I didn't have … insurance … Medicaid won't pay for the Trulicity … It was devastating, there was nothing I could do … I had to have an MRI and I was having problems with the insurance and they told me they wouldn't pay … They wanted $1700 … and I was like … I don't know where I'm going to get this money … I'm … unemployed*'" (P5). "*Unless they're really absolutely necessary, I don't … take tests*" (P13). "*Repeat tests of the same kind, I have in the past said, no I don't need to repeat this test … Financially, it's always very, very hard. We have had to do nothing but to pay for my medical expenses … Now with my medical stuff it's very, very difficult*" (P14).

Negative emotional impacts of denied or expensive medications and tests

Patients described negative emotional impacts and reduced financial freedom due to costs and denied insurance coverage. Frustration particularly followed the aforementioned cascade of work, and repeatedly exposing one's financial strain led to embarrassment and sadness.

Refusal of medications or postponement of tests

Some described refusing medications or postponing tests to avoid financial challenges. Four refused tests that were not covered by insurance or that they did not deem necessary. One refused inessential tests because medical bills had undermined her quality of life.

Patient perceptions of appropriate provider and patient roles in cost conversations

Providers should proactively offer assistance and tailor care to cost barriers

Most patients said providers should offer support for obtaining medication affordably, if available. Patients wanted prescribers to know their financial situation so prescriptions fit their budget (see

Table 3. Patient perceptions of appropriate provider and patient roles in cost conversations

Providers should proactively offer assistance and tailor care to cost barriers	“[If they could] *give the patient some discounts for all of the doctor’s fees or procedures, or make sure they can pay for the procedure before they actually perform them, it would be great. Because sometimes they just order it* [saying]: *‘Okay you have to get this thing done.’ But you do not know the cost ... It’s just hard to have to pay this amount of money.* [The doctor should] *ask ... can you pay this amount of money? You need some discount? You need any support?*” (P9). “*... point* [patients] *in the direction of being able to either get ... financial assistance or charity ... to say, “Hey, we have this program. We can see if you qualify” ... Or, if that hospital or that doctor’s office doesn’t have something like that, maybe point them in the direction of somewhere that may help. That way the person wouldn’t have to miss coming in and being seen because they can’t afford it ...*” (P1). “*I didn’t think I’m going to qualify for anything. And so like I think if I say, you know, this was really expensive I can’t afford it ... I kinda just assume, which is probably wrong, but I just assume that, like I don’t have an option because I do have a good income ... I’m pretty much just concluding that they’re not going to write it off for me just because I feel like it’s expensive*” (P12). “*Doctors should pretty much get with the medical part and should be the line of communication for the referrals or different resources*” (P18). “*Have a social worker coming in ... that’s what they do for a living, so you’d feel more open to them than you would just somebody that’s in the medical field ... their field is the medication than how you’d feel*” (P2).
Patients believe they are responsible for communicating their financial needs	“*... if you don’t communicate with your doctor about your employment needs, then you’re not going to get your medicine pal ... They’re not mind readers. They can’t prescribe me things if I don’t open up to them and let them know that I’m not working ... or my unemployment ain’t kicked in because of this Covid-19 ... I do have health issues and there’s things I do need, so is there some way you can give me some assistance where I can still get this medicine?*” (P7). “*So, if they know your financial situation, they might give you medicine that you can afford ... if I need help with my medication, then I gotta share and let them know that I can’t afford the medications*” (P13). “*The real shock is when you can’t afford your medicine. There are some doctors who can provide you with some of the medicine, but most doctors can’t*” (P14).
Unclear role of providers in test-related cost conversations	“*A lot of people can’t or are anxious about paying or trying to arrange payment plans. I think the billing office ideally should be able to understand your financial situation so they can work with you in some rational way to be able to chip away at it ... Installment plan*” (P4). “*I think ... a doctor ... it is not part of his job to ... help me with* [finances] *‘You’re going to charge me that much money and I cannot pay this much, can you give me a discount?’ I don’t know that me and the doctor are going to talk about that. That is more for like the billing people. But normally, just to talk to billing people and see what other help there is to get the procedure done*” (P9). “*I had to get some bloodwork done. At the time, I did have to pay out-of-pocket, but I got a bill and it was ... high ... I [did not talk to my doctor about the cost of that bloodwork as I] didn’t really think that was like a doctor issue ... the insurance I had wasn’t the best*” (P17).

Table 3). Patients thought that providers should provide a clear line of communication about assistance options and thought it appropriate for prescribers to proactively ask about their ability to pay. Most (72.2%) patients in our study preferred social workers to respond to needs and offer assistance, while only six (33.3%) of patients wished for their doctor to respond to needs.

Patients saw a limited role for providers in financial matters concerning tests. Some thought providers could not do much about test costs, so expectations did not extend to those expenses.

Patients believe they are responsible for communicating their financial needs

Four thought it was their responsibility to raise financial concerns. For them, prescribers would not know about their financial challenges otherwise.

Unclear role of providers in test-related cost conversations

Patients expressed confusion regarding providers’ role in alleviating test-related costs and did not typically expect providers to discuss test costs. Several thought the cost was out of everyone’s control, assumed the test was necessary, or thought providers did not know the cost. Four thought test-related financial matters were under the purview of the billing department, not the provider.

Informatics tools to facilitate conversations

Patients who expressed positive views regarding informatics tools thought tools could help facilitate cost conversations and SDM between patients and providers (see Table 4). Informatics tools should ensure that patients’ budgets are clear, costs are covered by insurance or affordable, patients are provided with options that account for multiple factors, and transportation logistics are incorporated.

Table 4. Informatics tools to facilitate conversations

Attitudes toward informatics tools in patient–provider cost conversations	"*I'd like* [if my doctor used a computer to help decide between medication options] *as long as they weren't staring at the screen the whole time [chuckles]*" (P12). "*That would be great* [if my doctor used a computer to help decide between medications]. *To figure out what's the cheapest, the one I can afford*" (P7). "*I think that'd be really helpful* [if my doctor used a computer to help decide between medication options] *. . . to get on a medication that I can afford and then you don't have all that time spent calling the doctor, calling the pharmacy, calling your insurance company*" (P2). "*I wouldn't mind* [if my doctor used a computer to decide on medications] *. . . I'm open to anything that the doctor says that will help me or help him*" (P18).
Clarifying patient's ability to pay	"*I guess if the doctor were to ask . . . I wouldn't be offended . . . if there was a question . . . to ask . . . 'around what range could you afford?' To see . . . that what they were going to prescribe would fall in that price range . . . I would be okay with a question like that*" (P1). "*I wouldn't care if he knows about my employment because if he send me a bill and I can't pay, then he'd be knowing*" (P3). "*If I can't afford the medicine, then why would my doctor prescribe me something . . . expensive when she can prescribe . . . a generic . . .?*" (P7). "*I want the computer to know how much I can afford . . . the price range of what I can afford*" (P17). "*So, if they know your financial situation, they might give you medicine that you can afford*" (P13).
Providing patients with choices	"[Cost] *depends* [on] *what pharmacies you use . . . if there was a tool to be able to put in multiple pharmacies for it to be able to show . . . is this medication cheaper at Walmart than CVS, a tool like that would help compare the cost between the pharmacies . . . to me that would be the biggest thing . . . if you're having a test done and it's cheaper if you do like a community hospital instead of like in the county. . . Just having those options to me, just being able to say, okay well we can do this test and it'll be X amount of dollars at this location*" (P1). "*Give a choice, like a pro and con . . . this is going to be good for you, this is going to be bad for you for, but this medication, is kinda comparable . . . Give me some choice, I can pick, you know? Because sometimes doctors just give you one choice . . .*" (P9). "*I would like it because then it gives you options, it gives you choices. It pulls you into the process . . . I think it would be neat for them to . . . talk through it with me. You know, like you can get this pill for $12 and this is the benefit and then we can get this pill for this cost. Or . . . an estimate. Like this one's less expensive or more expensive, the benefits, and maybe their rationale or their thought process behind which one that they would go to . . . what has the research shown about a particular medication. Like is it effective for the thing that I'm needing the medication for, the research. Cost analysis . . . the side effects, the benefit, and any scientific evidence for it*" (P12) "*. . . the side effects I would want to know . . . the reviews of other people. I need to know real reviews first before you put me on anything that you don't even know about for real . . . I want to know all options and I'll weigh the bad and the good? Because if it's not a good medication or if it doesn't really work well for other people, then I'd go a step up you know, and just try to make it happen*" (P17).
Incorporating transportation into decision-making	"*Maybe years back I avoided [a test] . . . due to transportation reasons . . . it was kinda scary because it was for my heart condition . . . I had to have one of my neighbors . . . get me there* [for the test]" (P18). "*I was supposed to get some type of procedure done and I didn't have anybody to take me . . . I just didn't have anybody at that time, so I just avoided it and did it later. Two years later though*" (P17). "*Put in my insurance. Check to see . . . what's covered, that way it will save me, not only the embarrassment but the time of trying to find a ride to somewhere that covers my medication*" (P18). "*Most of my appointments are in* [a different city] *. . . to get my eyes checked I couldn't do it because I didn't have the money to* [get there] *and public transportation said that they would come and get me, and they never did . . . I had to go without getting my eyes checked for a long time and I have cataracts . . . I don't have no vehicle . . . Last time I used public transportation, my appointment was at 10 o'clock in the morning . . . They came and got me at 7 o'clock in the morning, took me over there and that lady did not come back to pick me up until 5 o'clock . . . I sat at the hospital the whole time*" (P5).

Attitudes toward informatics tools in cost conversations and decision-making

Overall, 13 patients (72%) positively viewed the potential for informatics tools in patient–provider interactions. Seven were particularly supportive of the potential for SDM and information about clinical options and accurate costs. However, 2 of these expressed reservations if the technology would distract providers while 5 were open to using anything that the doctor thought would help.

Five shared concerns about technology use in patient–provider interactions. Three wanted their doctors to make decisions independently of technology, imagining technology replacing the doctor, rather than providing information.

Clarifying patients' ability to pay

Several saw a role for informatics tools to improve providers' awareness of their "financial situation," including employment status, insurance coverage, available budget, or balances for past-due bills and medical debts, which could translate to affordable medications and tests. Several expressed interest in information-sharing between providers and the billing department regarding payment plans and medical debts.

Providing patients with choices

Patients would have liked to weigh options, based on price and insurance coverage, side effects, clinical benefit, and necessity of the medication/test, in conversation with providers. Seven wanted to be aware of side effects prior to prescribing decisions. Patients wanted to make cost comparisons between pharmacies and testing facilities; several experienced varying costs based on location. If a medication or test was not covered by insurance or affordable, they would have preferred discussing options in the moment.

Incorporating transportation into decision-making

A few patients expressed challenges concerning transportation. An informatics tool could help by incorporating logistics into decision-making. Three mentioned missing tests due to lacking transportation, or relying on friends or family to get to the pharmacy. However, these challenges could be mitigated with a tool to support finding a ride to a pharmacy at the lowest cost.

DISCUSSION

Findings revealed that patients in our study want to discuss costs associated with medications and tests to obtain assistance from their providers or referrals to assistance programs. While some are comfortable initiating conversations about financial barriers, others prefer that providers initiate this conversation. Patients view cost conversations with providers about medication and tests as helpful, especially when providers proactively base decisions on costs or refer patients to cost-alleviation resources. Although patients understood that providers could assist with medication affordability, they did not perceive providers as having leverage to influence test-related costs. When the affordability of medications and tests is unaddressed in patient–provider conversations and subsequent decisions, patients are often left with a "cascade of work." Several patients developed practical strategies (eg, letting bills go into collections) for navigating systems do not work well for them and create a cascade of work (eg, calls and pharmacy double trips). Thus, findings contribute novel examples of patient "experiential" knowledge or expertise conceptualized in prior work.[62,63] Findings also reinforce the insight that experiential knowledge arises in part from creative and effortful work to negotiate resource limitations, while adapting illness management to one's local context.[63–65]

Our investigation revealed that patients in our study envision that informatics tools could facilitate cost conversations and SDM with providers, which may reduce this cascade. We also found that patients are often willing to self-report cost barriers, especially with providers with whom they have had a positive experience in the past. Using informatics tools, patients felt that they could make decisions about medications and tests if they could consider multiple characteristics of medication options simultaneously, such as cost-based on pharmacy/testing facility, clinical efficacy, and side effects.

Our patients reported they would like to discuss costs to obtain assistance from providers, which affirms previous work that has found positive consequences when cost conversations occur. For example, patients may receive medication substitutions or test alternatives,[66] office samples, nonessential medicine reduction,[67,68] or financial resources to help pay for medications.[29] Confirming findings by Dickert et al,[32] the patients in our study prefer avoiding surprise costs at the pharmacy. However, we extend prior work by showing that patients may want prescribers to know their budget, insurance coverage, and unpaid medical bills before prescribing new medications or ordering tests. Furthermore, findings extend prior research by showing that some patients also perceive a personal responsibility to share financial struggles to obtain support; this perspective might be leveraged through patient-facing tools to collect detailed, cost-relevant financial information. For example, tools might require the collection or assembly of information regarding income, employment status, outstanding medical bills, and/or budget for medications or tests. Furthermore, tools should facilitate cost conversations during consultations. Future research should explore privacy issues and patient perspectives regarding such data collection and sharing, and investigate whether providing such information prior to or during a clinical consultation can change clinical decisions.

Findings also underscore the need for healthcare providers to address costs proactively to prevent negative practical and emotional consequences for patients. We found that without cost conversations and clinical decisions that take cost barriers into account, patients are often forced to engage in a cascade of work to access cost-alleviation resources, medications, and tests. Previous research has highlighted negative consequences of unaffordable prescriptions, such as prescription abandonment,[13–15] multiple pharmacy use,[20] pharmacy callbacks,[20] and medication nonadherence.[16] We extend this by characterizing the resulting burden. Specifically, to obtain medications and complete tests, patients in our study engaged in effortful work that depleted their time, energy, and social capital. This resonates with a patient work perspective, which asserts that patient work should be supported through interventions; this perspective has found growing support in both health informatics and information science fields.[65,69–72] One type of informatics intervention to support patient work is digital decision aids; recent pilot projects[9,32] show the promise of patient decision aids that incorporate cost considerations (eg, Politi et al[73]). Interactive decision aids can convey benefit and risk information, improve SDM, and help overcome barriers to discussing costs.[57,74,75] Patients will make trade-offs and consider inconveniences (ie, higher dosing and generic alternatives) to reduce cost.[23,36] However, much work remains given that the majority of published patient decision aids do not address costs,[9,76] encourage cost conversations with a provider,[9] support individualization,[32] or communicate evidence of benefit to engage patients in cost–benefit analyses.[32]

The patients saw potential for informatics tools to support shared, cost-sensitive decision-making. Patients envisioned using informatics tools with providers to compare medication and test options, ensure affordability, and verify insurance coverage before a medication or test is ordered. This confirms findings that cost should be one type of patient value that enters into SDM technologies.[77] Our findings expand on prior work by outlining patients' interest in informatics tools which present medication/test costs and options, clinical efficacy, side effects, patient medical budgets and debts, and transportation logistics. One preliminary study has investigated including cost in an SDM tool geared specifically toward atrial fibrillation and found that it influenced patients' decision-making processes but not the ultimate medication choice.[78] Informatics tools could also deflect cost barriers by considering transportation logistics. We corroborated findings by Dillahunt and Veinot[79] that technology could improve healthcare accessibility by arranging transportation to testing facilities or pharmacies. Such tools should support patient information access before, during, and after discussions with providers, as providers likely will not have time in office settings for prescribing discussions. Furthermore, there is a need to reduce potential barriers to cost conversations, such as patient discomfort. Accordingly, patient-facing informatics tools might be conceptualized as "conversation starters" in a larger intervention.

While patients perceive providers as having control over medication costs through their decisions, patients think test costs are unknown to providers and out of everyone's control. They envisioned the integration of information between the billing department, providers, and hospital staff to centralize decision-making about tests and payment plans. Payment plans or other assistance programs would help patients remain financially solvent and avoid strategies with long-term negative impacts such as waiting for bills to go into collections to get payment relief. Increased coordination across healthcare providers, test sites, and billing might improve patient referrals to cost-alleviation resources prior to negative financial impacts.

In comparison with extant literature on providers' perceptions of cost-focused tools, patients in our study have similar goals and preferences. Both patients and providers want to minimize costs by surfacing information on patients' ability to pay and making out-of-pocket costs known.[29] While there was no consensus among providers on when or how to share patient-facing reports of costs (eg, portal, letter, and conversation),[29] patients would like their providers to share costs during consultations, before making decisions. Patients and providers also want informatics tools to support cost comparisons for medications and tests. Patients emphasized wanting to have side effect information when comparing medications to a greater degree than providers. Additionally, patients and providers want support in streamlining the resource referral process. Unlike providers, however, patients need more coordination between healthcare system departments, including billing. Together, these perspectives suggest a strong case for a new generation of informatics tools that proactively consider costs in clinical decision-making.

Our study has several limitations. Interviews were conducted in one health system in one region in the Midwestern US. Although this geographic limitation may reduce the generalizability of patient perspectives, we interviewed a diversity of patients with low incomes across ages and genders, which we view as a strength. This study took place during the COVID-19 pandemic, which further intensified patients' cost challenges and perhaps other struggles. Thus, future work should confirm our findings.

CONCLUSION

Patients viewed cost conversations as most beneficial when providers directly provided cost-alleviation resources. Although patients thought providers could help alleviate medication-related costs, they did not see how providers could influence test-related costs. When cost conversations did not occur, and affordability was unaddressed, patients faced a cascade of work, which they felt informatics tools could help prevent. Patients envisioned that informatics tools could facilitate cost conversations and SDM with providers by presenting patient healthcare budgets and debts, comparing medication and testing options, and considering transportation logistics.

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AUTHOR CONTRIBUTIONS

TCV, BEI, TRT, SRW, and JAP designed the study, including the data collection instruments. SRW recruited and consented participants. BI conducted interviews and verified transcripts. OKR, TCV, BEI, TRT, SEW, and JP developed the codebook along with 2 other Parkview Staff members. OKR conducted the main coding, and BEI conducted the coding verification. OKR and TCV drafted the manuscript, and BEI, TRT, JAP, and SRW reviewed the manuscript and revised it for critical content.

SUPPLEMENTARY MATERIAL

Supplementary material is available at *JAMIA* online.

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CONFLICT OF INTEREST STATEMENT

Three authors are employees of the health system where the research was conducted.

DATA AVAILABILITY

The data underlying this article cannot be shared to protect the privacy of individuals that participated in the study, as they could be identifiable from the qualitative interview transcripts generated in this research.

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