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Older Patient and Caregiver Perspectives on Medication Value and Deprescribing: A Qualitative Study

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Abstract

OBJECTIVES: Shared decision making is essential to deprescribing unnecessary or harmful medications in older adults, yet patients' and caregivers' perspectives on medication value and how this affects their willingness to discontinue a medication are poorly understood. We sought to identify the most significant factors that impact the perceived value of a medication from the perspective of patients and caregivers.

DESIGN: Qualitative study using focus groups conducted in September and October 2018.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article.

SETTING: Participants from the Pepper Geriatric Research Registry (patients) and the Pitt+Me Registry (caregivers) maintained by the University of Pittsburgh.

PARTICIPANTS: Six focus groups of community-dwelling adults aged 65 years or older, or their caregivers, prescribed five or more medications in the preceding 12 months.

MEASUREMENTS: We sought to identify (1) general views on medication value and what makes medication worth taking; (2) how specific features such as cost or side effects impact perceived value; and (3) reactions to clinical scenarios related to deprescribing.

RESULTS: We identified four themes. Perceived effectiveness was the primary factor that caused participants to consider a medication to be of high value. Participants considered a medication to be of low value if it adversely affected quality of life. Participants also cited cost when determining value, especially if it resulted in material sacrifices. Participants valued medications prescribed by providers with whom they had good relationships rather than valuing level of training. When presented with clinical scenarios, participants ably weighed these factors when determining the value of a medication and indicated whether they would adhere to a deprescribing recommendation.

CONCLUSION: We identified that perceived effectiveness, adverse effects on quality of life, cost, and a strong relationship with the prescriber influenced patients' and caregivers' views on medication value. These findings will enable prescribers to engage older patients in shared decision making when deprescribing unnecessary medications and will allow health systems to incorporate patient-centered assessment of value into systems-based deprescribing interventions.

Keywords

medication value; deprescribing; polypharmacy

INTRODUCTION

Polypharmacy, generally defined as the use of five or more medications, affects up to 35% of community-dwelling older adults and as many as 85% of older nursing home residents, placing them at risk of receiving potentially inappropriate or unnecessary medications.¹⁻⁶ Polypharmacy and inappropriate medication use in older adults is associated with adverse drug events, increased risk of hospitalization and death, and unnecessary medical expenditures.^{2,7-10}

To combat polypharmacy and reduce older patients' use of inappropriate medications, there is increasing interest in deprescribing at the prescriber, health system, and payer levels.¹¹ Deprescribing is defined as the systematic process of discontinuing or reducing the dose of medications whose harms outweigh their benefits within the context of a patient's clinical status, medication burden, and preferences regarding their care, with the goal of improving patient outcomes.^{12,13}

The attitudes of patients and caregivers toward medications and their openness to deprescribing varies.¹⁴ Because deprescribing is patient centered, it is essential for prescribers to better understand patients' and caregivers' perceived value of medications and factors that influence their willingness to stop a medication. However, prescribers have

identified barriers to deprescribing, many of which include assumptions about older adults' or their caregivers' views on medication use and value. Specifically, many prescribers feel that patients and caregivers would be resistant to stopping a medication^{15–17} and that deprescribing would jeopardize the doctor-patient relationship.¹⁶ Prescribers have also cited patients' poor understanding of medications and underreporting of difficulties surrounding medication use as making it difficult to engage in shared decision making centered around deprescribing.¹⁶

This discordance in views may, in part, explain why polypharmacy and exposure to inappropriate medications remains prevalent.^{15–17} Greater knowledge of patients' and caregivers' perspectives on medication value may empower healthcare providers to engage in shared decision making and initiate deprescribing conversations to mitigate the excess risk and costs associated with polypharmacy. Thus our objective was to identify the most significant factors that impact the perceived value of a medication from the perspective of patients and caregivers.

METHODS

Study Design and Sample

We conducted focus groups of older adults and caregivers in September and October 2018. We chose focus groups over individual interviews or a survey to facilitate collaborative conversation more effectively between participants.

We sought to conduct three to five focus groups each of patients and caregivers, with at least five participants per group, based on accepted qualitative research standards to achieve thematic saturation.¹⁸ We recruited community dwelling adults aged 65 years or older, or their caregivers, who had been prescribed five or more medications in the preceding 12 months. Patients and caregivers were not recruited as pairs, but all caregivers reported caring for an individual who satisfied recruitment criteria. We recruited patients from the Claude D. Pepper Older Americans Independence Center Research Registry at the University of Pittsburgh, a registry with more than 2000 patients aged 65 years or older who have consented to be contacted for research studies. We recruited caregivers from the Pitt+Me registry maintained by the University of Pittsburgh Clinical and Translational Science Institute that consists of approximately 195 000 research participants. We purposively sampled participants with diverse racial and ethnic backgrounds and who were enrolled in different types of health insurance (ie, Medicare, Medicaid, and private insurance) to ensure that diverse socioeconomic perspectives were represented.

Data Collection

The research team, composed of experts in qualitative methodology, pharmaceutical health services research, and low-value care, developed a focus group guide informed by literature (Text S1 and S2) that broadly addressed general views on medication value and what makes medication worth taking and how specific features such as cost or side effects impact the perceived value of medication. We also presented four real-life clinical scenarios involving potentially low-value medication use (Table 1). The final focus group guide and study

protocol were approved by the institutional review board of the University of Pittsburgh. Each focus group lasted approximately 90 minutes and took place on the University of Pittsburgh campus. Focus groups were led by an experienced focus group moderator (M.H. or A.D.), with an additional member of the study team present to take notes regarding the participants' contributions, group dynamics, and body language. Each member of the focus group consented to be audio-recorded. To ensure confidentiality, participants identified themselves by their first name or a pseudonym.

Codebook Development and Data Analysis

Focus group recordings were transcribed verbatim. A qualitative codebook encompassing concepts from patient and caregiver focus groups was developed by two members of the study team (A.P. and A.D.) using the editing organizing style as described by Miller and Crabtree³⁰ (ie, codes were developed inductively from the transcript content). The codebook was refined based on feedback from the principal investigator (PI) (T.R.) and an experienced qualitative methodologist (M.H.). The codebook developer (A.P.) and an experienced qualitative coder (A.D.) coded each focus group transcript using ATLAS.ti v.8, after which they met to observe consistency or discrepancies in their coding and reconcile any differences. Once coding was complete, the codebook developer (A.P.) and PI (T.R.) conducted a thematic analysis to determine the most salient themes within the data, noting key differences between patients and caregivers.^{31,32} Themes were then reviewed by additional members of the study team (A.D. and M.H.) as a form of investigator triangulation. Thematic saturation, defined as consistency and redundancy of perspectives (ie, no new perspectives emerged in the third focus group for each participant type), was achieved. Overarching themes with representative quotes from both patients and caregivers were reported.

RESULTS

Participants

We conducted three patient and three caregiver focus groups, each consisting of 3 to 7 participants, for a total of 16 patients and 17 caregivers. Although we attempted to have at least five participants per group to meet standard focus group criteria,³³ one caregiver group and one patient group fell short of that criteria due to unexpected no-shows and thus might be considered group interviews. All patients were 65 years or older, and caregivers ranged in age from 22 to 69 years. A total of 56% of patients were female compared with 82% of caregivers. Participants exhibited a variety of racial/ethnic backgrounds including white (seven patients, seven caregivers), African American (five patients, five caregivers), Asian (one patient, one caregiver), and American Indian/Alaskan Native (two patients). Five participants did not share their ethnic/racial background. Fourteen patients and 14 caregivers had cared for someone with Medicare or Medicaid with the remaining having private insurance. Ten caregivers cared for family members and seven were employed through homecare agencies, nursing homes, or group homes. They reported performing tasks including filling pill boxes, administering medications, performing or coordinating associated testing, or communicating with providers.

Key Themes

We identified four themes. (1) Perceived effectiveness, which manifested as subjective improvement in symptoms, objective improvement in clinical values, and disease prevention, was the primary factor that caused patients and caregivers to consider a medication of high value. (2) Adverse effects on quality of life, which manifested as severity of side effects and inconvenience and discomfort associated with administration, was the main factor that caused participants to devalue a medication. Participants also cited (3) cost, and (4) a strong relationship with the prescriber as factors they considered when attributing value to medication. Next we describe these themes and subthemes in detail. Table 2 lists additional representative quotes, and key differences between patients and caregivers are highlighted in Table 3.

Perceived Effectiveness

Subjective Improvement in Symptoms—Patients and caregivers valued a medication that they felt improved symptoms. For many participants, especially patients, this was the only reason they would consider a medication worth taking. One patient stated, “I’ve always looked at it not ... whether or not I needed it [the medication] beforehand, but whether or not it made me feel better afterward.” Specifically, participants cited examples where improving symptoms such as pain, anxiety and depression, or shortness of breath improved their quality of life and enabled them to continue participating in their daily activities. Patients and caregivers cited similar symptoms they hoped to target. Referring to her mother, a caregiver noted, “Her pain medication helped her to be able to still get around and [go] shopping ... so she can still get out and live a little bit.” Patients and caregivers also placed value on medications that resulted in immediate improvement in symptoms. When describing her husband’s preference for his albuterol inhaler over medications to treat chronic problems, a caregiver stated, “If you have an immediate relief of a symptom, you want to take the medication ... but if it’s something like long term ... [he’s] much more likely to forget it.”

Objective Improvement in Clinical Values—Patients and caregivers also valued a medication based on objective evidence in the form of improved clinical results. Patients often cited clinical values obtained at a doctor’s visit or via formal testing, such as blood pressure readings, cholesterol levels, hemoglobin A_{1c}, and bone density, because these markers provided objective evidence that a medication was effective. One patient stated that he does not check his blood sugars at home, but “I know mine’s working [because] I’m diabetic, because there’s one point my A_{1c} was 9.1 ... and now it’s down to 6.1.” Caregivers more commonly cited home blood pressure readings, but, overall, did not as frequently cite improvement in clinical results when determining a medication’s value.

Disease Prevention—To a lesser extent, patients and caregivers similarly valued a medication if they believed it was preventing a serious medical condition in the form of either primary or secondary prevention. In terms of primary prevention, participants cited examples related to the prevention of cardiovascular disease and considered medications to control diabetes or cholesterol worth taking given the perceived severity and risk of death associated with having a heart attack or stroke. Regarding secondary prevention, participants

provided examples related to preventing additional heart attacks or strokes and placed value on antihypertensives, statins, and antiplatelet agents. Patients and caregivers placed more value on medications for secondary prevention compared with primary prevention, especially those who had been previously resistant to taking medications. One patient stated, “I wasn’t really following up on all those medications ... and then I ended up having another heart attack ... and started taking my medications like I was supposed to.”

Adverse Effects on Quality of Life

Severity of Side Effects—Patients and caregivers most frequently cited side effects as the main reason they would devalue and stop taking a medication. Side effects that caused discomfort or adversely affected quality of life, such as drowsiness or fatigue, dizziness or lightheadedness, gastrointestinal upset, muscle cramps, and rash, made patients feel that a medication was not worth taking. They cited antihypertensives, statins, and metformin as medications they discontinued due to side effects. Caregivers cited similar side effects as patients but also found medications that resulted in confusion or altered mental status, such as benzodiazepines, to be of low value because they prevented their care recipients from carrying out daily activities.

Patients and caregivers would stop taking a medication if the side effect burden outweighed its perceived benefits. One caregiver stated, “I think if it’s debilitating in any form like nausea, vomiting ... diarrhea ... [and the side effects] are going to impact your life ... and your ability to do even basic things like leaving the house ... that’s when it’s not worth it anymore.”

Inconvenience Associated with Administration—Patients and caregivers also considered a medication to be of low value if it was inconvenient to administer. They cited inconveniences such as time of administration, need to coordinate administration with meals, or need to split pills as disruptions in their daily activities and therefore adversely affecting quality of life. Participants also indicated that associated laboratory testing, such as checking international normalized ratio, or patient-initiated testing, such as checking blood sugars, detracted from the value of a medication. Patients commonly cited injectable and time sensitive medications such as insulin when describing inconvenient medications. One patient stated, “I hate testing myself for my sugar ... and I don’t do it every day ... so I don’t take insulin, like after my meals.” Patients were more likely to devalue a medication if it was inconvenient to take, whereas caregivers were less troubled by the disruption and often felt that the benefit of a medication likely outweighed its inconvenience. A caregiver stated, “People are really taking medications because they really need these medications ... a slight disruption out of your day to take a few medications ... that it’s kind of worth it.”

Discomfort Associated with Administration—Patients and caregivers considered a medication to be of low value if the act of administering it was uncomfortable, again due to adverse effects on quality of life. This was especially true for swallowing large pills or injections, with insulin commonly cited. One patient stated, “They put me on an injection which I did not like, and I tried that for a while and went back to the doctor and said I can’t do this.” Again, patients were more likely to stop a medication if it was uncomfortable to

take, whereas many caregivers encouraged their care recipients to continue taking a medication because they believed potential benefit outweighed the discomfort.

Impact of Cost

Patients and caregivers had similar views on cost. Although factoring less prominently than other themes, they cited a medication's cost, as well as the cost of supplies needed for administration or related testing, as a consideration when determining its value. This was especially true if the cost of a medication caused them to make material sacrifices. One patient stated that he would stop taking a medication "when it's [the] choice between eating or not eating." A caregiver had a similar opinion, stating, "It's sad because seniors who are alone ... have to decide am I [going to] make this copayment for my meds ... that are medically necessary or [am I going to] pay the gas bill?"

Strong Relationship with the Prescriber

Neither patients nor caregivers specifically valued medications prescribed by certain types of healthcare providers, such as their primary care physician, nurse practitioners, or specialists. Instead, they valued the medications prescribed by providers with whom they had built good relationships. In general, caregivers placed more trust in the recommendations of prescribers, even without seeing direct effects in the form of improved symptoms or clinical values, compared with patients. A caregiver stated, "If a person's built a relationship, whether the doctor or nurse practitioner ... it's who has a relationship with them more so than the level of authority." Patients and caregivers also voiced their preference that various prescribers communicate with each other.

Clinical Scenarios

We observed an interplay of the themes just described when we asked patients and caregivers to consider clinical scenarios (Table 4). When considering scenario 1 (testosterone prescribed for fatigue), although the high cost of testosterone detracted from its value for many participants, both patients and caregivers overwhelmingly said that they would not take the medication because the possible side effects outweighed the potential benefit. One caregiver captured the opinion of most participants when she stated, "I think that \$200 a month is a lot of money just to treat tiredness, especially if it's going to increase the risk of having another heart attack."

In scenario 2 (switching from pravastatin to atorvastatin), participants had mixed opinions. Some felt "if I hear more effective for \$10 a month, I'm in," whereas others questioned, "Well, is the first one working? Why would you pay \$10 more for something that's the same?" This difference in opinion was consistent across both patients and caregivers. Most participants felt that they should check with their regular provider before making a change rather than taking the advice of a pharmacist alone.

In scenario 3 (clopidogrel no longer covered by insurance), participants stated that they would not trust their insurance company but rather seek the advice of a medical provider. Participants were even willing to pay for the medication out of pocket if their doctor recommended that they continue taking it. One patient stated, "The doctor should decide if

you need the medicine or not,” and a caregiver expressed a similar opinion stating, “I believe he should get in contact with his doctor.”

In scenario 4 (switching from omeprazole to an H2 blocker), most participants would change medications to reduce the risk of harmful downstream effects. One caregiver stated, “Side effects are the only thing for me.” Some caregivers did point out that “She’s going from one pill to two pills” and that the inconvenience would detract from the value of the new medication but would still choose decreased potential adverse events over convenience.

DISCUSSION

Among focus groups of older adults prescribed five or more medications, or their caregivers, we identified an interplay of factors that influenced their views on medication value including perceived effectiveness, adverse effects on quality of life, cost, and strong relationship with the prescriber, with differences between patients and caregivers. These themes were evident when patients and caregivers were presented with clinical scenarios asking them to determine the value of a medication and indicate whether and in what circumstances they would adhere to a prescribing or deprescribing recommendation.

Our findings build on prior studies by characterizing patients’ and caregivers’ perspectives on medication value with a greater degree of granularity. Consistent with prior studies, we demonstrate that perceived benefit is the primary reason a patient would wish to continue taking a medication^{34,35} and that side effects^{36–38} would make a patient consider a medication not worth taking. We further identified specific factors related to inconvenience or discomfort, such as frequency of administration and associated testing, which could be helpful to prescribers when identifying medications that a patient would be willing to discontinue. Provider trust was also shown to be a factor associated with a patient’s willingness to have a medication deprescribed.^{34,36,39,40} Our findings reinforce this in demonstrating that patients and caregivers valued medications recommended by providers that they trusted regardless of level of training.

Although prior studies have largely focused on patient perspectives, we identified the views of caregivers, a party with the potential to play an integral role in deprescribing, especially in older adults. Patients and caregivers shared some views on medication value, but they held nuanced differences of opinion, particularly regarding side effects, ability to tolerate inconvenience or discomfort, and degree of trust in prescriber’s recommendation. These differences may result in a patient and their caregiver placing differential value on medications and require prescribers to account for differing points of view. Our findings will provide prescribers with the prerequisite knowledge to initiate deprescribing conversations more meaningfully that account for the perspectives and values of both patients and caregivers, and they may also allow caregivers to act more readily as surrogates for patients who are unable to participate in these conversations.

By clarifying patients’ and caregivers’ views on medication value, our findings may also assuage prescribers’ concerns regarding potential negative consequences of deprescribing that have been shown to impede their willingness to deprescribe potentially unnecessary or

harmful medications. Barriers to deprescribing identified by prescribers in prior studies include assumptions about older adults' or their caregivers' views on medication use such as resistance to deprescribing,¹⁵⁻¹⁷ potential to compromise the patient doctor relationship if a medication is discontinued,¹⁶ and patients' poor understanding of their medications.¹⁶ Our findings counteract these assumptions in demonstrating that a number of factors would make a medication not worth taking for patients and caregivers and that they place a great deal of trust in a prescriber's recommendations.

We also showed that patients and caregivers were able to weigh these factors, especially evident when presented with clinical scenarios, indicating they would be able to participate in shared decision making and engage in conversations surrounding deprescribing. This is further supported by studies that show patients who were more aware of medication harm and the term "deprescribing" were more likely to initiate conversations related to deprescribing.⁴¹ By understanding factors that impact patients' and caregivers' perceived value of a medication, prescribers and health systems can more ably identify and prioritize medications in conjunction with patients that they would find mutually acceptable to discontinue.

Our study has important limitations. Although using qualitative methods allowed us to explore patients' and caregivers' perspectives on medication value with a greater degree of nuance, our findings may not generalize to all older adults or their caregivers. The older adults in our focus groups were community dwelling, from one geographic region, and able to participate in the focus groups, so it is possible that nonparticipants with poorer health, from a different geographic region, or with different prescription drug benefit coverage may have different views on medication value. Moreover, caregivers were not purposively sampled according to caregiver type, so it is possible that not all caregiver views were represented. Nevertheless, we did purposively sample patients and caregivers from a variety of sociodemographic backgrounds and who were enrolled in different types of health insurance. Lastly, although two focus groups consisted of only three participants, no new themes emerged after conducting multiple focus groups, indicating thematic saturation.

In conclusion, our findings suggest that a number of factors including perceived effectiveness, adverse effects on quality of life, strong relationship with the prescriber, and cost influence patients' and caregivers' value assessments of and willingness to discontinue a medication, with important differences between patients and caregivers. These findings may aid and empower prescribers in initiating conversations and engaging in shared decision making with patients and their caregivers that is essential to successful deprescribing.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Clinical Scenario Focus Group Prompts

Scenario	Focus group prompt
Scenario 1	Mr. A is a 75-year-old man who has heart disease. He tells his doctor that he is more tired than usual. The doctor checks some blood tests, prescribes him a testosterone cream to use every day because it may help reduce his tiredness, and tells the patient to follow up for his physical in a year. (A 30-day supply of testosterone costs \$200). The patient is worried because his pharmacist told him that testosterone may increase his risk of having another heart attack. ¹⁹⁻²²
Scenario 2	Ms. S is a 65-year-old retired woman who has high cholesterol and diabetes. She has taken the same medication, called pravastatin, to lower her cholesterol for the past 10 years. She gets a call from a pharmacist who works at her doctor's office telling her that a medicine more effective at lowering her cholesterol and preventing heart attacks and strokes, called atorvastatin (Lipitor), is available. ^{23,24} He asks her to switch to the new medication. The new medication costs \$10 more a month.
Scenario 3	Mr. R is a 68-year-old newly retired man. He receives a letter in the mail from his new Medicare Advantage insurance plan telling him that a medicine called clopidogrel (Plavix) that his doctor prescribed is no longer necessary and will not be covered by his insurance. He's been taking this medicine since his heart attack 10 years ago. He does not understand why his doctor would refill this medicine if he did not need it.
Scenario 4	Mrs. T is a 70-year-old woman who takes a medicine once a day called omeprazole (also known as Prilosec) for acid reflux. She has been taking this medication for the past 3 years and feels that it works well to control the chest discomfort she was experiencing from acid reflux, which was very bothersome to her and prevented her from eating what she wanted. Her doctor recently recommended that she stop the medication or switch to a different medicine that she would need to take twice a day, due to the concern that long-term use of omeprazole may increase her risk of fracturing a bone ²⁵⁻²⁷ and may also be associated with the onset of dementia (ie, Alzheimer's disease). ^{28,29}

Table 2.

Key Themes and Supplemental Quotes

Themes and subthemes	Patient quote	Caregiver quote
Perceived effectiveness		
Subjective improvement in symptoms	"I do not take many, but my choice in when I would take them is particularly symptomatic issues."	"Just as long as it's [medication] making the person's life livable, they can function during the day ... help them feel ... I say 80 to 90% better."
Objective improvements in clinical values	"I have high blood pressure but it's under control ... I know it skyrockets if I do not take the medications."	"My husband takes ... one for blood pressure ... and that's tested every time he goes into the doctor's office."
Disease prevention	"I took it because I did not want to have stroke or something."	"I think if the medication is being prescribed ... to prevent something that the person may be at risk for but does not pose many risks or harms to the patient, then it's worth taking."
Adverse effects on quality of life		
Severity of side effects	"As far as myself, I'll stop taking a medication which I have before when it starts making me get symptoms I did not have before"	"For me it would be if my mom wasn't present ... and she's miserable, then to me that tells me it's just not ... worth it ... she's not with us mentally, she's just here; that's not quality of life."
Inconvenience associated with administering a medication	"If I had to take it more than twice a day ... if you have to remember during the day ... I know getting the pills in would not work."	"My mom was taking a few inhalers ... until it got to the point where she could not actually manipulate the inhaler."
Discomfort associated with administration	"The size of pills. I have trouble ... with the huge [pills]."	"I'm thinking about my grandfather's situation ... if his sugar stays too high, then he [will not] heal and that's how he lost one foot, so he has to take his sugar ... it's very worth it ... so that little bit of discomfort for him, well you could take that."
Impact of cost		
	"If my meds ever go to where they were impacting the quality of our life outside of whatever these medical issues should be, yeah it would be too expensive. I do not think I would run my family into debt to pay."	"You [have] to take care of your necessary bills ... I will make sacrifices if I had to go [without] cable ... I'll do what I have to do ... if you cannot afford it you just cannot, I'm not gonna go and rob a bank."
Strong relationship with the prescriber		
	"I'd be happy with anyone who's prescribing if they are listening."	"A team approach is always best to put all the heads together and kind of decide what works."

Table 3.

Key Differences in Themes between Patients and Caregivers

Themes and subthemes	Patients	Caregivers
Perceived effectiveness: objective improvement in clinical values	<ul style="list-style-type: none"> Relied on clinical values obtained at doctor's visits or via formal testing 	<ul style="list-style-type: none"> Relied on home readings
Adverse effects on quality of life: severity of side effects	<ul style="list-style-type: none"> Cited side effects that caused discomfort or adversely affected quality of life such as fatigue, dizziness, gastrointestinal upset, cramps, rash 	<ul style="list-style-type: none"> Emphasized confusion or altered mental status
Adverse effects on quality of life: inconvenience associated with administration	<ul style="list-style-type: none"> Would stop a medication that is inconvenient to administer 	<ul style="list-style-type: none"> Would encourage care recipient to continue medication despite inconvenience due to potential benefit
Adverse effects on quality of life: discomfort associated with administration	<ul style="list-style-type: none"> Would stop a medication that is uncomfortable to administer 	<ul style="list-style-type: none"> Would encourage care recipient to continue medication despite inconvenience due to potential benefit
Strong relationship with the prescriber	<ul style="list-style-type: none"> Valued prescriber opinion but often placed more value on subjective or objective evidence 	<ul style="list-style-type: none"> Placed trust in prescriber despite seeing NO improvement in form of improved symptoms or clinical values

Table 4.

Clinical Scenarios: Focus Group Prompt and Supplementary Quotes

Clinical scenario	Patient quote	Caregiver quote
Scenario 1: Testosterone prescribed for fatigue	"The medication might increase his chances of a heart attack. I think that's [the] more important question than the \$200 I think."	"I'd rather have him be tired than chance having another heart attack."
Scenario 2: Switching from pravastatin to atorvastatin	"I would recommend to her to go ahead and try it... For ten dollars, try it for six months [and] see what she thinks."	"It's not that huge of a difference between those two drugs to make it worth paying more for something, especially if you are already on something and it's working."
Scenario 3: Clopidogrel no longer covered by insurance	"You could not just quit your med because of that."	"Why would an insurance company be doing the work of a doctor?"
Scenario 4: Switching from omeprazole to H2 blocker	"The new medication does not have the side effects that the doctor's worried about."	"If there was something else I could take and it did not have those risks associated with it, then that's fine. And then she would have to take the new medicine twice a day, taking away the inconvenience of just once-a-day Prilosec... but unless there was something better, I would not have asked her to stop."