Strategies for Coping in a Complex World: Adherence Behavior Among Older Adults with Chronic Illness

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BACKGROUND: Increasing numbers of medicines increase nonadherence. Little is known about how older adults manage multiple medicines for multiple illnesses.

OBJECTIVES: To explore how older adults with multiple illnesses make choices about medicines.

DESIGN: Semistructured interviews with older adults taking several medications. Accounts of respondents' medicine-taking behavior were collected.

PARTICIPANTS: Twenty community-dwelling seniors with health insurance, in Eastern Massachusetts, aged 67–90, (4–12 medicines, 3–9 comorbidities).

APPROACH: Qualitative analysis using constant comparison to explain real choices made about medicines in the past (“historical”) and hypothetical (“future”) choices.

RESULTS: Respondents reported both past (“historical”) choices and hypothetical (“future”) choices between medicines. Although people discussed effectiveness and future risk of the disease when prompted to prioritize their medicines (future choices), key factors leading to nonadherence (historical choices) were costs and side effects. Specific choices were generally dominated by 1 factor, and respondents rarely reported making explicit trade-offs between different factors. Factors affecting 1 choice were not necessarily the same as those affecting another choice in the same person. There was no evidence of “adherent” personalities.

CONCLUSION: Prescribing a new medicine, a change in provider or copayment can provoke new choices about both new and existing medications in older adults with multiple morbidities.

KEY WORDS: patient compliance; drug therapy; patient-geriatric; health behavior; qualitative research.

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INTRODUCTION

Good outcomes in chronic illness depend on self-management by the patient, often including appropriate use of medicines. About 25% medicines prescribed for long-term conditions are not taken as directed.^{1,2} Harm caused by nonadherence to appropriately prescribed medicines is significant.^{3–7} Cost of illness in the US caused by nonadherence is estimated at \$100 billion per annum,⁸ referred to as the nation's “other drug problem.”⁹ Medication adherence increases with higher income and reduced medication costs, is variably related to age, gender, marital status, ethnicity, education, social support and presence of depression or cognitive impairment, number of prescribing physicians, and use of multiple pharmacies.^{1,10–13} Increased numbers of medicines increase nonadherence^{13,14} because of increased complexity^{15–20} or cost.^{12,21–24} Increased age is not associated independently with reduced adherence.^{13,25}

Chronic conditions are associated with continually changing symptoms, severity, stigma and future risk, all of which affect adherence to health-promoting behaviors, including medicines. Medication nonadherence also arises from concerns about specific medicines.^{26,27} No perceived necessity of the medicines or concerns about their safety or efficacy may lead to nonadherence.²⁸ Medicines also have a symbolic role, which may cause a general resistance to taking them.^{26,29} People seek to understand or evaluate their medicines initially before deciding whether to take them, and over time,²⁹ making choices about treatment options within their own belief and preference framework.^{27,29}

Medication adherence is dynamic in that daily decisions are affected by situational factors and constantly renegotiated. In evidence-based health care analytic decision-making is promoted to assess the costs and benefits of a choice.³⁰ However, people in their daily lives use shortcuts (“heuristics”) to simplify complex mental processes.^{31,32} It is likely that this type of decision-making occurs in health-related behaviors. Patients may assess

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fully the costs and benefits of a choice, or a dominating factor, such as cost of a medicine, may provide a shortcut such that they ignore other factors such as symptom control.

Previous work has concentrated on patients' decisions about a particular medicine for a specific condition. Little is known about how patients taking multiple medicines for multiple illnesses prioritize their medicines. Understanding these processes may help prescribers and researchers to design more effective adherence interventions.

We conducted a qualitative study to understand how older adults taking multiple medicines make decisions. We collected accounts of beliefs about medicines and medicine-taking behavior. We also collected accounts of historical choices between medicines, accounts of potential ("future") choices between different medicines, and factors influencing these choices.

METHODS

Participants

This study was part of a larger study funded by the U.S. National Institute on Aging examining cost-related under-use of medicines in insured elderly adults. The original cohort was community-dwelling older adults from Harvard Pilgrim Health Care, a New England HMO with about 800,000 members, 7% over age 65. Each respondent has a \$600 annual cap on medicine reimbursements and pays a \$5 to \$35 copayment per prescription. Of the original study cohort ($n=198$), 73 were taking more than 3 medicines. After Institutional Review Board approval, we purposively sampled 20 participants to reflect key factors potentially affecting adherence: sex, income, illnesses generally considered symptomatic (such as GI disease and arthritis) versus asymptomatic (such as hypertension and hypercholesterolemia) and mental health medication. Table 2 provides information on the distribution of the key variables used for sampling. People prescribed medicines for dementia were not approached. We interviewed 71% of 28 people invited to participate. Four could not be contacted, 3 declined, and 1 had entered a nursing home.

Data Collection

Interviews were conducted by RAE in patients' homes. We removed all references to "adherence" or "compliance" from the interview to reduce socially desirable responses. Interviews (45–90 minutes) were carried out between January and March 2005 and taped with permission. Table 1 summarizes the themes explored.

Corrected transcripts were imported into Atlas.ti 5 software (Element 5, Eden Prairie, MN 55344, USA).

Table 1. Themes covered in interviews

Themes
– Previous experiences with current and past medicines and diseases
– Knowledge and beliefs about the current and future impact of the disease
– Knowledge and beliefs about the effectiveness, side effects, complexity, and cost of current and past medicines
– Influence of prescribers, the health care system, media, and family
– Influence of medicines' costs and sources of funding for medicines
– Accounts of historical choices made between medicines; prioritization of current medicines; accounts of future choices that would be made between medicines

Table 2. Characteristics of interviewees

Interviewee characteristics	Number (n)
Sex	12 female, 8 male
Ethnicity	18 white, 2 African American
Mean age (range)	76 (67–90)
Income category	1: <\$100 ($n=4$) 2: \$1,000–\$2,000 ($n=6$) 3: >\$2,000 ($n=9$) 4: not known ($n=1$)
Living arrangements	14 living with partner (8 men, 6 women) 5 living alone (5 women) 1 living alone in sheltered accommodation (1 woman)
Geographic location	Boston (2) Suburban Boston (12) Other Massachusetts (6)
Presence of comorbidities (number of interviewees)	Hypertension (15); hypercholesterolemia (15); ischemic heart disease (5); heart failure (3); thromboembolic disease (2); mitral valve disease (1); arrhythmia (1); GI disease (7); pain (6); neurological pain (4); arthritis (3); leg cramps (2); gout (1); migraine (1); diabetes mellitus (6); osteoporosis (5); glaucoma (3); macular degeneration (3); anxiety (5); depression (2); ADD (1); cancer undergoing treatment (3); allergies (2); psoriasis/eczema (2); COPD (2); asthma (1); other (6)
Mean number of comorbidities (range)	5.4 (3–9)
Mean number of drugs (range)	7.2 (4–12)
Number of respondents prescribed:	
Antihypercholesterolemics	15
Antihypertensives	15
Mental health medication	8
Analgesics	11
Gastric acid-suppressing agents	7
Instrumental activities of daily living (IADL)	
Number of respondents able to carry out the following:	
Preparing meals	18
Managing money	20
Shopping for groceries or personal items	17
Performing light or heavy housework	17
Using a telephone	20
Had vision problems*	0
Formal or informal care giver helping them taking their medications	Formal (0), informal (2)
Use of a "pill box" or other memory aid to aid adherence	Pill box (3); written or printed chart (12)

*Assessed by ability to read medication labels

Analysis

We developed a coding framework using constant comparison. Coding was informed by published research, themes presented by interviewees, discussion with team members, and refining the fit of codes to emerging themes.^{33,34} The early interviews asked participants to prioritize their current medicines. This triggered accounts of actual choices about previous medicines and theoretical choices about current medicines. These

accounts provided rich information about the basis for choices between medicines, alongside the prioritization of current medicines. The initial sampling frame did not need to be modified as this theme emerged. RAE carried out initial transcript coding, and this was verified by the other authors and a pharmacist with qualitative research experience (see Acknowledgments). After 15 to 16 interviews, we identified no more new factors affecting adherence. The remaining interviews confirmed this saturation. We verified transcript coding by examining whether consensus was achieved with a sample of quotes across all themes and interviewees, and found very close agreement.

We read individual narratives to identify historical and future choices made about medicines, and the main factors that influence them. The results presented focus on the analysis of these choices.

RESULTS

We interviewed 12 women and 8 men (see Table 2). We stopped interviewing when we reached thematic saturation (no new factors affecting decision-making emerged).

Overview of Medicine-taking Behavior

Interviewees gave in-depth accounts of their medicine-taking behavior. Interviewees usually knew why they were taking their medicines, and there were only 2 instances of factually incorrect information about medicines offered. Our approach prompted discussion of instances of “non-adherent” behavior in all interviewees. We did not aim to quantify levels of nonadherence, but it was clear that adherence to individual medicines ranged widely. If an interviewee reported nonadherence to 1 medicine, this did not appear to be associated with nonadherence to other medicines. Experimenting with regimens ranged from stopping a medicine altogether; taking regular breaks; discontinuing medicines to check if they are working, or to determine the cause of side effects, trying individual medicines in a complex new regimen; and reducing doses. One patient reported stopping taking their antihypertensives to increase symptoms before a consultation. Prescribers were often not consulted before interviewees changed regimens.

“I’ve tried to stop taking those tablets [carbamazepine] for a while and I got a really bad pain in my face and it made me cry and I went back to my doctor and he said you’re stupid. Don’t stop taking those medicines.” (76-year-old woman, 11 medicines, 5 comorbidities)

No interviewee wanted to take more medicines than they were already taking. There was general resistance to taking medicines, particularly evident when interviewees discussed mental health medicines.

Do People Make Choices Between Medicines?

The transcripts revealed 41 historical and 40 future choices between medicines. All interviewees had made at least 1 historical choice leading to adjusting dosing, swapping, or stopping a medicine, and discussed at least 1 future “hypothetical” choice.

In both historical and future choices, interviewees described choosing between medicines for different diseases (such as prioritizing treatment for glaucoma over hypertension); and choosing between medicines for the same disease (such as rejecting a third inhaler). Most historical choices were between medicines for the same disease. Interviewees described choosing between medicines and other health-related behavior (such as diet).

What Influences People’s Choices?

Factors, or domains, influencing choices between medicines were symptom control, side effects, fear of future risk of the disease (affective forecasting), medication cost, negative health experience, illness beliefs, and “acceptability” (administration route and palatability).

Specific concerns or beliefs about a medicine or illness dominated more general factors such as influence of family members, friends or media, health care providers, or income. General factors appeared to have a moderating effect.

In this cohort, there was no dominant disease, medicine, or factor for making choices. For example, 15 interviewees had hypertension, but in the reported choices, hypertension dominated or was dominated equally often. Individuals did not use the same factor for all choices.

Prioritization of current medicines and hypothetical future choices were usually influenced by medicine effectiveness or symptom control (15 choices) and concerns about future risk of the disease (13 choices).

“I think the blood pressure medication [is most important], the propranolol and the amlodipine.....I think there’s a lot of people walking around with high blood pressure and they don’t know it and they could, I mean, easily have a stroke, you know” (75-year-old woman, 10 medicines, 8 comorbidities)

However, analysis of historical choices showed that these were typically provoked by side effects (15 choices) and costs (7 choices). Discontinuation was more likely if the interviewee also reported doubts about the importance of the illness. Respondents were prepared to stop unpleasant regimens (such as potassium tablets), unacceptable presentations (such as injections), or medicines with unacceptable side effects.

“The reason I don’t like to take it [diuretic], because I have to go and urinate so many times a day, it gets so discouraging, and it gets so strong, the feeling that if I ever left the house I’d be in trouble.” (87-year-old woman, 5 medicines, 5 comorbidities)

When choosing between medicines for 1 illness, factors discussed by interviewees were generally side effects, cost, effectiveness, and acceptability. Interviewees wanted the medicine with fewer side effects, or lower costs, or the 1 perceived to have most effect on that disease.

When choosing between medicines for different illnesses, the most common factors that influenced choices were: fear about future risk of the disease and symptom control. Interviewees chose the medication for the disease where they were most concerned about future risks from the illness if it was not controlled.

"like the other day.. I run out of the Zocor [simvastatin] because picking up the eye medicine was more important to me, so I got that. And I have to wait 'til I get some more money to pick up the Zocor. So, that's how I played it,....I pick up the one that's most important, like, um... I'm going to be needing high-blood-pressure medicine, but it was more important to pick up the Zocor." (71-year-old woman, 6 medicines, 4 morbidities)

Alternatively, they chose the medication that they felt had the best symptom control, irrespective of the disease it was treating.

"I have a feeling the Beconase would strike me as more important [than the atenolol] for my comfort, for my noticing." (77-year-old man, 5 medicines, 6 comorbidities)

When choosing between medicines and other health behavior, factors that led to reducing medicine use in favor of other health behavior included side effects and resistance to taking medicines.

"She gave me some stretching exercises that seemed to help an awful lot. I was able, finally, not to take the [celecoxib] and still get along pretty well. I keep it here if I wake up someday with a really sharp pain." (77-year-old man, 5 medicines, 6 comorbidities)

How Important are Complexity and Cost of Regimens?

As complexity and cost of regimens are known to lead to increased nonadherence, the effect of these factors was examined in our cohort. Complexity was not considered a problem by interviewees. No one reported his or her regimen as difficult to remember. Unintentional nonadherence was reported infrequently, although self-report of forgetting to take medicines can be expected to underestimate actual levels. Nearly all interviewees had written memory aids or "dosette" boxes, which may suggest that such a high number of medicines triggers active coping mechanisms to deal with the complexity. Also, most medicines were once daily regimens, unlike multiple-dose regimens, which are more difficult to follow.³⁵

In contrast, increased medicine costs led to interviewees modifying regimens or rejecting medicines outright. This was linked not just to income, but also attitudes about paying for medicines and distrust of the health care system. Cost was a dominant factor for interviewees with very many medicines and appeared to result not just from financial hardship. Interviewees expressed feelings of unfairness or resentment when having to consider costs for many medicines.

"I said my God, what do they think I'm a bank here or what! I have a lot of pills. But if they [prices] jump like that I'll have to start cutting them in half or stop taking them. So a few of them that I haven't been taking I don't take them anymore. Just can't afford it." (76-year-old woman, 11 medicines, 8 comorbidities)

Do People Use More Than 1 Factor When Making Choices?

Choices influenced by 1 dominant factor ("heuristic") were much more common than "analytic" decisions using multiple factors, with the presence of a dominating factor effectively excluding consideration of other factors for that particular choice. Only in the absence of dominant factors did people carry out analytic decision making.

"Because when I took them [antihypertensives], I started to take them one a day to see what symptom they're trying to give. Today I take quinapril, tomorrow I take the next pill and we can see what the reaction it's going to give me. And it didn't give me no reaction.... If I do anything or rush myself, it will go up a little bit and then it comes down. You feel like hyper. You feel like swinging in the head. If your pressure goes down, you're sweating. Yeah, if you don't take it, you get sick. That's why you take medicine. I need my medication.... You've got to buy them, you got to find a way. I cut down buying a pair of shoes....I can cut corners with my food. (71-yr-old woman, 6 medicines, 4 morbidities)

Furthermore, individual interviewees reported both single and multiple-factor-choice mechanisms for different decisions.

DISCUSSION

This small exploratory study suggests that elderly people with chronic illnesses appear to make many choices between medicines. Within 1 individual, choices made about different medicines can be driven by different factors and adherence to 1 medicine does not appear to predict adherence to other medicines.

The key finding of this study for practitioners is that in real-life ("historical") choices about medicines, interviewees use different factors from the ones they discuss in hypothetical ("future") choices. When the choice was hypothetical, people used their beliefs about the importance of treating the disease and symptom control to inform their decision. In real life, side effects, high perceived cost, or lack of effectiveness were the most commonly reported factors influencing choices of medicines, very frequently leading to reductions in medicine use. These historical choices reflected the impact of external forces, whereas future choices are more reflective of abstract elements such as people's perceived future risk for morbidity and mortality, and valuations of their treatment.

Judging the effects of an illness from recalled experience ("experiential" rating) is different from predicting its impact ("affective forecasting").³⁶ This is because without previous experience of an illness, people imagine the loss of health caused by the illness, rather than life with the illness. In our small sample, both experience of an illness and fear of its future effects appeared to have a similar influence in promoting adherence.

Usually, side effects, high perceived cost, or lack of effectiveness dominated the decision process, such that people did not consider anything else, but used 1 of these factors as a shortcut to help them make a choice. This process of "fast" decision making has been characterized elsewhere.³¹ In choices discussed in our study, if a dominating factor (such as cost) was present, elderly people did not appear to make multifactorial analytic decisions. However, it is possible that

people's decision-making often has a component that is subconscious and was not articulated during our interviews. In this case, patients are not explicitly aware of all the factors affecting their medicine-taking decisions. This requires further investigation, using methods such as discrete choice experiments to explore the relative importance of a range of factors.

Many people do not discuss their concerns about medicines with their prescribers, which means that factors influencing choices are not identified and addressed. This finding supports other evidence that patients and prescribers do not discuss concerns about medicines,³⁷ which may lead to poorer adherence.^{13,38,39}

Our findings suggest that external factors such as changes in coverage, economic circumstances, or providers or initiation of a new medicine can provoke a choice between medicines. For example, moving from Medicaid to Medicare Part D has changed coverage and copayments for a substantial subgroup of the US elderly chronically ill population,⁴⁰ and this is likely to have provoked choices between medicines. Changes to an already complex regimen appear to change the "equation" for the patient, and provoke a further round of (unwanted or forced) choices.

LIMITATIONS

This study was limited by its small sample size, drawn from a cohort of cognitively competent elderly patients with multiple morbidities in 1 HMO. We stopped interviewing when we had identified all the factors affecting choices that occurred across the medicines presented. We cannot say that the dominant factors that emerged here can be generalized to different age groups or geographical locations. We do not know the level of education of the participants. Our cohort nearly all used memory aids, which may not be representative of the wider population of older adults. The value of these qualitative data is their ability to reveal complexity that cannot be uncovered from quantitative surveys.⁴¹ This approach obtains descriptions of strongly held attitudes and private behaviors to inform research and interventions in medicine-taking behavior.

IMPLICATIONS FOR POLICY, DELIVERY, OR PRACTICE

This study suggests that older people with multiple chronic illnesses have complex behaviors related to medication use that may not be well understood by prescribers, researchers, or policy makers. Older people with multiple morbidities make many choices between medicines. Choices influenced by a single dominant factor ("shortcut") are more common than multifactorial "analytic" decisions.

These results suggest that there are no shortcuts to effective medication counseling. Ongoing, regular discussion with patients about each of their medicines is required, and for patients with multiple chronic illnesses, this requires coordination of care across specialties. To influence patient choices such that they use their medicines optimally, we need to gather information on current preferences and prior historical choices. Patients may have different priorities from their prescribers. Each new medicine potentially sets off new choices by the patient, which may or may not be discussed with prescribers. Good clinical practice requires prescribers to engage in dialog with their patients when a new medicine is prescribed.

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RAE, DRD, ASA, DGS, and SBS contributed to the drafting of the paper. Dr Katherine Payne, University of Manchester, contributed to the development of the coding schedule and carried out interrater reliability. RAE is guarantor.

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