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“It’s a toss up between my hearing, my heart, and my hip”: Prioritizing and Accommodating Multiple Morbidities by Vulnerable Older Adults

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Abstract

Nearly three quarters of older adults have multiple morbidities (MM). This study investigated which morbidities older adults prioritize, why, and how they accommodate these conditions, focusing on elders with two or more chronic conditions and low socioeconomic status.

Methods—In-depth interviews were conducted with 41 older adults (most-being African American women from the southeastern U.S., with two or more chronic illnesses).

Results—Many participants reported worrying most about their heart disease, diabetes, and disability/mobility problems, and about their synergistic effects. Many worried that MMs might tip them into a downward spiral. Participants spent the most time and money on arthritis and diabetes. Few received help; when they did, relatives assisted with arthritis/ mobility, diabetes, and effects of stroke.

Discussion—Enhanced formal care coordination, increased use of technological innovations, and understanding elders’ priorities are necessary to improve self-care/management and quality of life.

Keywords

Multiple morbidity; older adults; African Americans; self-care; self-management

In a study published in 2002, approximately 70% of those 65 and older reported two or more co-occurring chronic diseases, contributing to the over 60 million Americans with multiple morbidity (MM).^{*} Multiple morbidity is increasing: in just over 10 years, 80 million Americans will have multiple chronic conditions.¹

Multiple morbidity presents numerous challenges to older adults, including frequent interactions with the health care sector, increasing out-of-pocket health care expenditures,

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^{*}We use the term *multiple morbidity* (MM) to describe the co-occurrence of two or more chronic illnesses, as opposed to *comorbidity* in which conditions are linked with an index disease under study.

and complex (sometimes contradictory) self-care regimens. Compared with individuals having only one chronic condition, individuals with MM are more likely to classify their health as fair or poor, are twice as likely to indicate that they have bad health days, are more likely to have activity limitations, and use significantly more health services.²⁻⁴ Out-of-pocket medical expenses are considerably higher among individuals with MM and tend to increase over short periods of time. A recent study found that older adults with two, three, and four co-occurring conditions sustained 41%, 85%, and 100% increases in out-of-pocket expenditures, respectively, over four years.⁵

Such out-of-pocket expenditures may be particularly burdensome for lower socioeconomic status older adults, who are more likely than others to experience multiple morbidity.⁶ Such elders often contend with environments with few resources, including limited health insurance, insufficient access to medical specialists, a lack of continuity of care, challenging transportation situations, and inadequate social services to assist in meeting prevention and self-management goals.⁶⁻⁹ Furthermore, many existing approaches and assumptions of how those with MM should manage their conditions fail to incorporate what McMullen and Luborsky call *evaluative rationales*, or “the cultural logic or idioms employed to rate one’s health according to a set of criteria”¹⁰, p. 437,¹¹

The goal of this study—to understand how vulnerable older adults with MM prioritize and manage their chronic conditions—is a critical task for several reasons. First, the majority of existing literature on MM care focuses on formal management, while most individuals attempt to prevent, contain, or manage illnesses on their own or in conjunction with advice received from health care professionals, family members, or other personal relations. Despite the acknowledged importance of self-management or self-care, lay perspectives on MM self-care remain virtually unexplored.¹² In addition, since the association between perceived health priorities and optimal health behavior is well documented,¹³ and self-care is critical to successful MM management, it is essential to understand how and why older adults prioritize their illnesses. Programs and policies designed to support elders, families, and providers in optimizing self-care must be linked with existing perceptions of illness and priorities.^{14,15}

Project impetus, approach, and purpose

The researchers were motivated to conduct the current study by findings from a previous project, an investigation of the challenges faced by vulnerable older adults in managing congestive heart failure (CHF) (N. Schoenberg & G. Rowles, unpublished data, April 2006).

The project, called *Experiential Dimension of Health Care*, was a two-year long focused ethnography on how ten older adults from rural or inner city environments negotiated their health care for CHF. Since CHF is a serious, medically demanding condition that requires extensive self-management,¹⁶ we assumed these ten individuals would prioritize this condition and that it would serve as an excellent lens through which to see how low-income, vulnerable elders negotiate the health care environment. Through our repeated in-depth interviews, however, we learned that certain illnesses, even if less life threatening or less medically demanding, took precedence over CHF. Moreover, *Experiential Dimensions* participants, including the informant below, suggested important complexities and contradictions in their multiple regimens:

You got your shortness of breath—that’s bad because I got to walk outside the two blocks and wait for the bus and there ain’t no bench right there. And then I got to climb up those stairs and transfer to the next [bus] station. All to see the doctor and get my pills and such—for my heart. It takes the day. But it ain’t nothing I can’t handle—I been living with inconvenience and difficulty my whole life. What

makes it hard is juggling the real problem—my thyroid cancer. Now that’s something serious and I got to think—will this medicine that I’m on for the heart failure be bad for this? My heart doctor tells me to lose weight, but I seen those people with cancer shrink down to nothing and I don’t want to get down too low. It’s complicated and makes me crazy sometime. If I had more money, I’d hire me a secretary. It’s a juggling act and I ain’t a good juggler. (Ms. H, African American woman, age 58)

Such insights into challenges of MM self-care caused us to reexamine our assumptions concerning which conditions take priority and why. Throughout their narratives, participants provided insights that “resist[ed] and restructure[d] ideas of normalcy that d[id] not fit with their experience,”¹⁷ p. 89 contradicting a more clinical notion of which illnesses should be prioritized and accommodated and why.¹⁸ In addition, such observations made us aware that the experience of MM is more than the sum of the individual illnesses.

Methods

We undertook a three-stage in-depth interview protocol. The first stage, consisting of traditional ethnographic interviews,¹⁹ involved a discussion of general domains rather than specific questions about MMs. This stage allowed us to identify topics salient to those with MM rather than basing initial interpretations on researchers’ assumptions. Five pilot interviews (with three women and two men, 50 years old and older, each with two or more chronic conditions) revealed that individuals give special attention to illnesses that they see as worrisome, including those causing pain, increasing risk of complications, or potentially disabling them. Priorities and worries were manifest in expenditures of money, time, and personal assistance.

Following this stage, we developed an interview guide that incorporated semi-structured and open-ended questions on worry, time, and resource expenditures, and need for informal assistance (i.e., non-professional help, generally provided by a family member, friend, or acquaintance). This questionnaire was pretested with four new participants to ensure linguistic appropriateness, to eliminate repetition or to capture overlooked issues, and to minimize participant burden (see Appendix). After the questionnaire was revised, we began our third stage, in which we engaged 41 middle-aged and older lower-socioeconomic status adults in in-depth interviews about their personal circumstances, health history, perceptions, and self-care approaches toward their multiple morbidities.

Sample eligibility and recruitment procedures

Since our goal was to describe how those elders most vulnerable to health and resource insufficiency prioritized and accommodated multiple morbidity, we focused on elders with multiple chronic conditions who lacked resources. Our intention was not to compare vulnerable elders with a general population or to focus on any specific personal characteristics (such as race or gender), but rather to include those most likely to experience MM and to do so under challenging circumstances (i.e., low socioeconomic status). Inclusion criteria included: (1) having received a diagnosis of at least two chronic illnesses; (2) having “just enough money to get by” or “not enough money to make ends meet” (participants’ subjective assessment of financial security), a risk factor for both MM diagnosis and factors associated with suboptimal self-care (lack of health insurance, insufficient access to healthy foods or exercise facilities);²⁰ (3) being 55 years old or older (the age when MM rates escalate, particularly among those of lower socioeconomic status);²¹ and (4) being able and willing to engage in at least one interview session. We excluded those who did not meet the inclusion criteria above as well as those who were unable to speak English, extremely hard of hearing, or too ill (mentally or physically, as determined

by the elder and the interviewer) to complete the interview. The gender and race composition of our sample (higher percentage of women and of African Americans) reflects our project's emphasis on vulnerability due to health status and resources. The heterogeneity of the sample is, from our perspective, an accurate reflection of those in our geographic area most likely to experience multiple morbidities and resource constraints.

Theoretical saturation, or the emergence of no new information, dictated our sample size; minimal new insights emerged after interviewing 40 individuals (but we had already scheduled an interview for one additional participant, giving us a final count of 41).²²

Our team recruited participants from two senior citizens' centers, two low-income senior housing complexes, two churches, and one civic meeting. We selected these locations for the diversity of lower-income older adults (elders who were relatively healthy use the Senior Center and attend the churches and civic meeting, while those at the senior housing complexes may be homebound). Our predominantly female sample may reflect our recruitment sites, since more women than men attend senior centers and churches; however, as women greatly outnumber men in later life and have significantly higher levels of poverty and multiple morbidity, this overrepresentation of women may be warranted.²³

Once the directors of these organizations agreed to allow us to discuss our project during a congregational meal or special meeting, we organized a presentation about multiple morbidities; interested older adults from the senior center, church, housing development, or other community organization attended the information session. Upon completion of our presentation, individuals were encouraged to talk further to project personnel and to complete a screening sheet determining their project eligibility described above. Of those who completed the screener, all but four were determined to be eligible and enrolled in the study when the interviewer followed up.

Interview procedure and protocol

Our anthropologically-trained interviewer verified participant information, restated the purpose of the study, and arranged for an interview session when she made a follow-up telephone call. Most interviews took place in participants' homes and were tape-recorded unless the participant expressed a preference that it not be. After the interviewer obtained informed consent, participants answered open-ended and semi-structured questions on life and health history and MM, including self-care strategies. To establish the time spent on self-care activities, we worked with the participant to complete an hour-by-hour activities diary. Interviews lasted 90–120 minutes and often took place over two sessions. The duration of each interview depended on the participant's loquaciousness and fatigue and the interviewer's ability to keep the participant on the topic. After the completion of the interview, the participants were thanked for their time, provided with a gift card to a local supermarket, and sent a handwritten thank you note from the principal investigator, a letter summarizing our results, and an invitation to a reception where the researchers expressed their appreciation and where researchers and participants discussed the study findings. All protocols were approved by the University of Kentucky Institutional Review Board.

Data analysis

Data were analyzed using an iterative approach. After the tapes were professionally transcribed, our research team repeatedly read the transcripts, independently engaged in line-by-line coding, and regularly met to ensure similar coding orientations and to discuss emerging themes and patterns. We initiated line-by-line coding rather than culling themes according to the pre-established template of the interview questionnaire; thus, although the questionnaire helped focus the topic, most themes emerged organically. We compiled a

codebook, defining and adding new codes, as needed, to refine it and to determine consistency within the line-by-line coding. Consistency was assessed by comparing the coding for identical transcripts; differences among the codes were discussed until a consensus was reached.²²

Once the coding scheme and codebook were established, we used the qualitative software package NVivo to improve organization, management, systematic coding, and coding retrieval.²⁴ Upon completion of the line-by-line coding in NVivo, three coders pursued additional line-by-line and axial coding¹¹ and began to categorize codes and themes conceptually.²⁵ Validation checks, including assessing intercoder reliability and engaging in member checks, occurred throughout the analytic procedures, as did interpretation of results.²⁶ This iterative process of coding, sharing codes, debating concordant codes, and re-coding was repeated until we ultimately established an intercoder reliability ratio of .85.²⁷

Results

Sample characteristics

Table 1 displays the sample's sociodemographic and health background. Participants, the vast majority of whom were women (85%), ranged in age from 55–90 years, with an average age of 70.4. Approximately two-thirds of the sample was African American, with the remaining third White. Race was assessed through an open-ended question (“What race do you consider yourself?”). This self-assessment yielded some unconventional replies (e.g., “human race,” “Italian”) leading to the category of “other.” Interviewer notes suggest that the interviewer would have assessed these four “others” as White.

About equal numbers of participants were married (39%) as widowed (44%), with the remaining 17% being divorced, separated, or never married. About one-third achieved less than a high school education, 40% graduated from high school, and the remaining 32% achieved some or a complete college education. Approximately one-third of participants had an annual income below \$10,000, with most of the rest (50%) earning less than \$30,000. Forty-four percent reported good health and 42% reported fair health despite the high prevalence of hypertension (93%), arthritis (78%), and diabetes (44%). Other common chronic conditions included cancer (27%), stroke (10%), and many miscellaneous conditions (34%), such as kidney disease or lupus. The average number of conditions was 2.3 per person, ranging from 2–7; the five most common configurations were arthritis and hypertension (27%); hypertension and diabetes (17%); arthritis and heart disease (17%); hypertension and heart disease (12%); and arthritis, hypertension, and heart disease (5%). All participants were from an urban or suburban context in the southeastern United States.

Priorities

Table 2 provides insights into which chronic condition produced the most worry and required the most time, money, and help. Of the 93% of the sample with hypertension, for example, only small percentages noted that high blood pressure was the most worrisome (8%) or required the most time (16%), money (13%), or assistance (5%). Heart disease, diabetes, and the combined effects of MM were most worrisome for our sample. Elders spent the most time and money on diabetes, the combination of various multiple illnesses, and arthritis. Most reported receiving relatively little help from informal sources, but when they did get assistance, children (especially daughters) and grandchildren (generally granddaughters) tended to provide it for diabetes, post-stroke care, and arthritis. Although bladder problems constitute a major source of worry and time, the condition is relatively rare (three participants reported having the condition). In the next section, we explore why and how people with MM prioritized certain conditions.

Explicating worry

Which conditions were the most worrisome depended on perceived seriousness, the presence of physical sensations, the threat of functional decline, and self-care demands. Many participants focused on one condition they considered more serious than the others, as did the 74-year-old who stated, “I’m really scared of the cancer. Anything new happens to me I’m thinking ... it may be cancer involved with it. Because I’ve developed a history of it because I’ve had it two or three places.” Another informant expressed worries over her elevated blood pressure:

When the blood gets so high, the heart and everything can just stop beating. Then it’s easy for you to get blood clots and you can go into stroke. You can go into a stroke and might not come out of it. That’s the reason why I think it’s all important for your health but that pressure is a serious problem. (Ms. L, African American woman, age 76)

Complications from the combined effects of MM worried many informants, including this participant with high blood pressure, high cholesterol, and arthritis:

I’m really concerned with all of them. I know [the ones that] will take me on out of here would be my high blood pressure and my cholesterol. Now I know arthritis is a discomfort but I don’t have the crippling kind and if I did that would be a concern also. After a time the disease progresses—you may get so you can’t walk or have to walk with an aid of a walker or whatever. But I don’t have that kind and I got these other things. (Ms. S, White woman, age 68)

The symptom experienced provoked worry for many. Several participants, including the speaker quoted below, suggested that asymptomatic conditions are a matter of concern because they sneak up on you without warning and are associated with serious conditions.

Well I really do worry the most about the high blood pressure. ‘Cause see you know you got arthritis and you can tell when it’s coming on. But you can’t hardly tell about high blood pressure. It can just hit you like that [snaps fingers] when that blood goes up. (Ms. L., African American woman, age 76)

Others harbored concerns that discernable sensations associated with their chronic conditions would diminish their functional abilities; for example, many worried that side effects from their antihypertensive medications would change their lives or that arthritis would immobilize them. A 63-year-old White man with high blood pressure, arthritis, and diabetes noted, “Well right now my biggest worry is my shoulders, the arthritis because I have this swelling, too. Because it limits me and may get worse.”

As the narrative below by an informant with high blood pressure, arthritis, and hypothyroidism indicates, elders with MM draw on others’ or their own experiences of symptoms and functioning to compare their current state of health and functioning to their former functioning (loss) or to that of people with more advanced or complicated cases of the same condition or conditions. When participants compare themselves with others, the usual benefits of a downward comparison (“at least I’m not as bad off as Mary”) fail to bring comfort because they foreshadow their own impending functional losses.

I worry about the arthritis the most. I saw what it did to my husband and how his knees were the first to go and then his hips and his joints deteriorated and gave him a great deal of pain and then he got to the point where he didn’t want to move around because it hurt so much, which wasn’t good for him. It might have contributed to him dying. It restricted him. He was a very active man. He did a lot of volunteer work. He remodeled things at church like the cafeteria. He remodeled the kitchen. Painted all the classrooms. He was always working at home all the

time. He went from that to just somebody that sat in a chair and hurt and gained weight because ... his whole lifestyle was gone. It hurt him to even get in the car so he didn't want to leave but if he got in the car, it took a long time to get him out. If we left in the morning we didn't come back till dark cause once he was in there and driving he enjoyed it so much. Other than that he just sat home and was in pain. (Ms. C, White woman, age 77)

In addition to symptoms, side effects, and increasing limitations, worry about self-care capacity shaped how elders prioritized their conditions. Another informant talked about the demands of high blood pressure, diabetes, arthritis, and chronic kidney failure.

My kidney failure [worries me] because they tell us all the time if we don't do our dialysis we would die. Even when you do the dialysis your immune system is slow and with my phosphorous it'll go up and cause you to have a heart attack. It can cause your arteries to clot up and there's so many things that works against it even though I look healthy, there are so many things you have to worry about and even when my blood pressure dropped so low, I could go into a stroke. There's just so many things. (Mr. P, African American man, age 57)

Another participant with heart disease, high blood pressure, diabetes, and high cholesterol, worried about her suboptimal self-care:

... I know that I haven't lost any weight and I haven't been exercising so I worry about it. Yeah, I worry about it and my cholesterol being high but basically the CAD [coronary artery disease] is why I worry about my cholesterol so ... it's a lot, especially combined. (Ms. T, White woman, age 66)

Time

As our activities diary demonstrated, self-care and formal medical management consumed a lot of time, particularly for arthritis/mobility, diabetes, and the synergistic effects of MM. Arthritis was described as extremely time-consuming because it incapacitates people physically, causing them to spend a great deal of time on fundamental activities such as bathing, preparing food, and getting out of bed. For conditions requiring medication, a lot of time is committed to adhering to a regimented schedule. Dietary planning requires balancing medication, food intake, and physical activities; resolving conflicting medical advice; and developing new ways of preparing food.

Juggling several conditions consumed more time than management of a single condition. For example, inadequate mobility stemming from congestive heart failure or arthritis made self-care activities (e.g., obtaining prescriptions or checking diabetic feet) more time-consuming and difficult for many informants. A participant discussed how her arthritis incapacitates her, making self-administered insulin injections time-consuming and challenging:

Let's see, probably the diabetes or the arthritis and I have to think about the two together. Well, I stick my finger twice a day but probably with the arthritis because you know it moves it around. It may hurt in one area in the morning and somewhere else at noon and somewhere else at night so I have to deal with that and the diabetes. (Ms. B, African American woman, age 66)

Resolving self-care conflicts occupied extensive concern and time, as stated by this informant with high blood pressure, arthritis, and an overactive bladder.

Well I believe the overactive bladder is more time-consuming than the others. ... I mean that's all there is to that. Well he [the doctor] told me to drink plenty of water

for the rest of my problems, and see with the overactive bladder, you're bound to be going to the bathroom. (Ms. R, White woman, age 67)

Participants also alluded to numerous formal medical encounters, including multiple doctor visits (varying specialists, not coordinated on the same day or locations), regular physical therapy, and rehabilitation. Tinkering with types of medicines and dosages, balanced with polypharmacy, sometimes required several trips (and financial outlays) to the doctor's office. An informant with high blood pressure and diabetes stated,

When my blood pressure started out cutting up it took her [the doctor] several times before she could get it where she wanted it. She kept changing my medicine. Come back and we'll check. I paid \$71 for a bottle of medicine. She said I'm sorry but I've got to change this medicine. Said it's too much for you. If the fluid gets too much for you then it makes you heart jump real fast. You have to get up in the night and everything cause it's pounded too bad. Then I go back to the doctor and she said stop taking that. I want you to take this. I take what they tell me to take so I don't have a problem. But it takes time to get it all right. (Mr. A, African American man, age 68)

Despite these challenges, most elders acknowledged accommodating their schedules to manage complex MM by fitting the self-care requirements into their lives. For those without many external demands, this accommodation replaced a previously replete schedule (e.g., employment or fastidious housekeeping). Elders with numerous demands, including paid employment, caregiving responsibilities, and very active retirement lives, pushed self-care into the available space in their schedules. These participants described a full schedule of events in which self-care activities such as medication-taking or exercising had to fit in with other responsibilities.

Finances

Informants described how self-management for each individual chronic condition, most particularly for diabetes and arthritis, presented challenges. Many conditions have expensive medications that must be taken frequently and regularly, involve over-the-counter (OTC) or alternative therapies, have multiple components, necessitate multiple doctor visits, and/or require management strategies that are not covered by insurance or public programs. One 71-year-old African American woman pondered, "The most expensive? Probably high blood pressure pills. 'Cause I take three of them. Usually my arthritis medicine lasts me a little longer because I don't have to take that on a daily basis."

The financial outlay to manage these conditions appeared to be more than simply the sum of expenditures for each condition. As discussed by this informant with celiac disease, thyroid disease, and diabetes, a standard self-care dietary regimen winds up demanding multiple financial resources.

The celiac disease—it's tough and expensive with my other health issues. I have to be really careful about what I eat. I can't eat wheat and really anything that might be processed could be a problem. So I got to do special things, like going to the health food store to buy all of these different grains. But that really costs me a bundle and it makes it hard to manage my diabetes, which requires a different diet where you better not eat too many carbohydrates like potatoes. I can have potatoes with the celiac. Rice too. But, see, they tell you what to eat if you have diabetes, but I can't stay on those foods with the celiac. It's a very special diet that winds up costing me about \$100 a week and it's just me at home now. (Ms. P., White woman, age 58)

Ms. P's careful dietary balancing act takes a toll on her finances, particularly since her major self-care activities are not covered by health insurance or special programs. Indeed, our participants generally note that affording MM self-care was contingent on insurance coverage, availability of samples or other "freebies," and, to a more limited degree, family assistance. Diabetes was viewed as costly due to the medication expenses, syringes, and blood glucose testing equipment, some of which is not covered by Medicare. Lack of insurance coverage, for such things as eyeglasses or hearing aids, was a source of great concern to many, such as this woman with six chronic conditions:

I need a new hearing aid, but we've just gotten him [her husband] two new ones, so you can't do it all. Medicare does not pay for glasses for older people or hearing aides. What kind of life would we have if older people weren't wearing glasses or having a hearing aid? Think we've got traffic accidents now [laughs]! I don't think that's right, but they don't [pay for them]. (Ms. D, White woman, age 75)

In response to these multiple financial demands, participants used resources strategically to meet their self-management needs. They discussed many ways to manage expensive medical regimens—by drawing on employer-based health insurance, seeking care at federally qualified health clinics or local public health departments, receiving samples from their physicians, receiving "cut-rate" medicines, and making strategic decisions. Such strategic decisions often involved foregoing devices or self-care activities (hearing aids, exercise programs), as is discussed by this 68-year-old African American man: "My doctor tells me it would be good for my sugar [diabetes] to take some exercise, but it's hard—the rent, food, my medicine, it adds up. Joining a club's not going to work."

Assistance

Most elders expressed little need for help, indicating that they were able to handle the self-care tasks for now (e.g., "I really don't get help with any of them, I just take my medication" and "... So far I don't need help, but if it's something, if I had to carry something heavy or something, they would do it for me"). Assistance, mostly from children and grandchildren was sought mainly when pain (arthritis) or disability (post-stroke) prevented elders from performing certain activities or driving. For instance, some participants reported that daughters picked up prescriptions or brought by sugar-free food items.

Despite the modest incomes of people in our sample, these small purchases were the only mention of monetary assistance. However, many participants also were wary of what might lie ahead, noting that if anything were to change in their medical coverage, their physical health, or their daily expenditures (e.g., rent increases, larger health insurance co-payments) they would be more financially vulnerable and might have to ask for help.

Rather than ask for help now, many participants indicated that they simply no longer pursued certain activities because of limitations imposed by their chronic conditions. A strong ethos of independence pervaded most narratives about receiving help from others, including the following statement from a participant with high blood pressure and arthritis:

Well I don't get a lot of help from anybody cause I live by myself and I take care of my apartment and I do my groceries and things and some things the kids will do but not too much. 'Cause the way I feel about it, the longer either physically and mentally, the longer I push to do these things, the longer I will be able to do them as I age in life. That's the reason I like doing things for myself. (Ms. P, African American woman, age 76)

The drive to return to former health and diminish their reliance on others was a pervasive theme among those who required some help. Such an ethos is apparent in the words of this informant with severe arthritis and mobility limitations:

I get all the help that I feel is necessary. Maybe through time I would like more help but ... I get a ride to church. I don't drive anymore 'cause I gave my car to my grandson but everywhere I want to go, I call somebody and if they're going I get a ride. I don't have any problems with transportation. In fact before I fell when I would go to the doctor I'd leave the hospital and walk down to the senior center and get on the bus and come home. But I know now I can't do that. I don't want to press myself. Maybe later on it might even get better. I'm hoping it will anyway. (Ms. F, African American woman, age 82)

Given our modest sample size and the sample's relative homogeneity, it is difficult to arrive at definitive conclusions about similarities or differences according to race/ethnicity or gender; however, we did not sense discernible differences in perspectives on worry, time expenditure, or assistance. Such similarities in perspectives may reflect the predominance of women, especially African Americans, in the study. The sole area where race/ethnicity appeared to coincide with views expressed was in finances. African American women seemed to express more worry overall about ability to pay for multiple chronic condition self-care than other groups, perhaps reflecting their greater degree of poverty.

Discussion

Elders with multiple morbidities worried about and prioritized disabling conditions, such as arthritis, and serious health threats, such as diabetes, heart disease, and the synergistic effects of multiple conditions. This worry and prioritizing manifests itself in resources (time, money, and informal assistance) expended on these conditions. Elders' discussion of the conditions they prioritized and why they did so made intuitive sense. Moreover, such prioritization conforms to epidemiological data that show these conditions to have wider prevalence and greater potential for complications than other illnesses. For example, 49.5%, 18%, and 31% of all older adults (aged 65+) have been diagnosed with arthritis, diabetes, and heart disease, respectively.²⁸ Even middle aged adults show high prevalence of these chronic conditions. Among those aged 51–61 participating in the Health and Retirement study, 37%, 10%, and 13% had a diagnosis of arthritis, diabetes, and heart disease, respectively. Among this same age group of African Americans, the prevalence of these three conditions is even greater at 40%, 17.5%, and 14%.²⁹

Diabetes and hypertension, on their own or as risk factors for other conditions, constitute major health threats, consume extensive resources, and receive extensive clinical attention. Arthritis and mobility challenges are not only extremely common, but perpetually defy an elder's ability to live a pain-free and fully functioning life; however, since there are more limited and efficacious treatment options, arthritis appears to be less highly prioritized in clinical practice.³⁰ Lay concerns about the synergy of MM have been addressed in formal, coordinated clinical management, but have seldom been described in patient self-care. This study remains one of the first to provide insights into what conditions elders consider important, and why and how they accommodate MM.

Consistent with Becker and Newsom's findings on the resilience of older African Americans with chronic illness³¹ and many of McMullin and Luborsky's self-appraisal results,¹⁰ the middle aged and older adults in this study have demonstrated remarkable adaptability and perseverance in the face of serious health challenges. Participant narratives and activities diaries revealed strategic accommodation of MM, including allotting a great deal of time to self-care activities, figuring out ways to pay for expensive treatments, and, even without drawing on many informal networks, juggling these numerous and complex combinations of chronic illnesses. Despite the fact that an objective health and resource assessment would predict otherwise, these older adults appeared to be doing well, managing to accommodate

their health challenges into a livable schedule and budget, and offering hopeful assessments of their futures.

Resilience

Our data suggest that, over years of challenges, older adults have developed resilience and strategies that equip them with a remarkable ability to accommodate multiple chronic conditions. Employing resilience strategies may buffer risk factors and provide opportunities for overcoming disadvantages (e.g., fewer resources, stressful life conditions) that may have accumulated over a lifetime. Dealing with challenges throughout their lives appears to have taught participants strategies to manage difficult situations, including prioritizing or focusing attention on particular conditions and management activities.

Prioritizing certain conditions and self-management actions over others may serve as one of several weapons in a “survival arsenal”³¹ that buffers disadvantage. As is suggested by cognitive theories (such as socio-emotional selectivity theory, in which social relations are intensified and deepened in focus³²) and selective optimization and compensation theory (in which activities are narrowed by choosing certain ones over others³³) giving special attention to certain chronic conditions may help older adults consolidate their health management activities. For many elders in our study, high priority is given to medication, with little mention of such self-care being excessively demanding, too time-consuming, or otherwise onerous. Participants focused on conditions such as heart disease, diabetes, and disability/mobility problems, as well as the synergistic effects of the combination of these conditions. Prioritization of such morbidities allows other conditions (sensory deficits, cancer, bladder problems) to take up less time. With limited time, resources, and emotional energy, older adults in this study and others make strategic choices that optimize their health and well-being.³⁴

Limitations

Although this paper fills a significant gap in the literature by highlighting how vulnerable older adults prioritize and manage MMs, it is not without limitations. First, since we intentionally focused on how adults with few resources deal with MM, we cannot claim our results are generalizable to a larger group of elders. Furthermore, as a qualitative study, our sample size was adequate to meet the requirements of theoretical saturation, but does not allow us to claim generalizability even to other vulnerable elders. Other limitations related to sampling frame include a disproportionate inclusion of women (who are more likely to have MMs and be represented in the older, minority population) and participants from one small city in the southeastern U.S. In addition, because self-report was used rather than medical records or other secondary information sources, there may be some error with disease diagnosis, income level, or other issues. Finally, in the absence of caregiver interviews, the modest extent of informal assistance reported by our informants cannot be corroborated.

Implications and future directions

Understanding what MMs elders prioritize and why is a necessary step toward improving self-care and buffering the growing trend of MM and associated health, quality of life, and financial complications. Like many clinicians, older adults prioritize diabetes, heart disease, and the convergence of several chronic conditions, but they also place great emphasis on conditions that might further disable them.

Coordination of these conditions, both clinically and in the realm of self-care, is imperative. Elders in this study were acutely aware of the likelihood for these MM to worsen over the coming years and the potential for them to be left physically and financially vulnerable.

Despite their resilience and well-stocked survival arsenals, participants expressed a good deal of uneasiness at the prospect that one additional or worsening MM might tip them into a downward spiral. Such a possibility was deeply disturbing not only for its implications for health, pain, and quality of life, but also for what this spiral might mean to their independence. Maintaining current functioning, including not becoming more vulnerable to symptoms, side effects, complications, or financial problems associated with MM, was viewed as necessary in order to retain independence, a goal of evidently great importance.

Our findings demonstrate the need to consider the synergy of MM rather than to focus on one chronic condition at a time. Although insights related to the formal management of multiple chronic diseases have led to innovative developments, including the Chronic Care Model and the Chronic Disease Self-Management Program,^{35,36} this study is one of the first to examine lay perspectives on MM self-care.¹² As Fried et al. suggest, although complexity is inherent in the management of MM, providers and patients must strive for management wherein “the care of patients becomes predictably complex.”³⁴, p. 250 Such comprehensive medical management, including self-care, is essential and management repertoires must expand to fit the multiple and increasingly complex array of challenges facing older adults. Promising technological improvements, including home health monitoring devices and communication enhancement technologies lend promise to independent living. Such assistive technologies range from modest modifications like the home installation of ramps, lifts, and improved lighting to technological aids that remind individuals to take medications at the right time.³⁷ Home automation control systems or “smart homes” anticipate residents’ needs and monitor daily activities, provide memory support, and can be tailored to the precise needs of the individual.³⁸ In addition to these technological enhancements, drawing on elders’ existing and successful strategies, improving our understanding of their priorities and the ways in which they accommodate MM, and embarking on more equitable and effective approaches to containing illness is essential to caring for an aging America.

Notes

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Appendix

Partial list of questions asked during in-depth interviews

We're trying to understand how people deal with having several different diseases at the same time.

Which of your illnesses do you think you spend the most time on? Why?

Which do you worry about most? Why?

Which do you get the most help with? Why? From whom?

Which do you spend the most money taking care of?

Now, I want to ask you the opposite questions:

Which of your illnesses do you think you spend the least time on? Why?

Which do you worry about least? Why?

Which do you get the least help with? Why?

Which do you spend the least money taking care of?

Table 1**DEMOGRAPHIC CHARACTERISTICS (N=41)**

Variable	n (%)
Sex	
Male	6 (15%)
Female	35 (85%)
Race/ethnicity (self-described)	
White	11 (27%)
Black	26 (63%)
Other	4 (10%)
Age, mean=70.4, s.d.=8	
55–64	10 (24%)
65–74	16 (39%)
75–80	9 (22%)
80 +	6 (15%)
Marital status	
Married/partnered	16 (39%)
Divorced/separated/never married	7 (17%)
Widowed	18 (44 %)
Educational attainment	
Less than high school	12 (29%)
Graduated high school	16 (39%)
Some college	9 (22%)
Graduated college	4 (10%)
Annual Income (2 missing)	
\$10,000 or less	12 (29%)
\$10,001–15,000	6 (15%)
\$15,001–20,000	4 (10%)
\$20,001–25,000	4 (10%)
\$25,001–30,000	6 (15%)
\$30,001–40,000	3 (7%)
\$40,001 or more	4 (10%)
Health Status (1 missing)	
Excellent	—
Very good	3 (7%)
Good	18 (44%)
Fair	17 (42%)
Poor	2 (5%)
Health conditions	
High blood pressure	38 (93%)
Arthritis	32 (78%)
Diabetes	18 (44%)

Variable	n (%)
Heart Disease	14 (34%)
Stroke	4 (10%)
All Others	14 (34%)
Health insurance	
Medicare + company sponsored	25 (62%)
Company sponsored	9 (22%)
Medicare + Medicaid (dual eligible)	4 (10%)
Other	3 (6%)
Number of people living in the household	
One	16 (39%)
Two	17 (42%)
Three	6 (15%)
Four or more	2 (5%)
Current employment status	
Not employed	35 (85%)
Employed	6 (15%)

Table 2

PERCENTAGES OF PARTICIPANTS WITH CHRONIC CONDITION^a AND GREATEST WORRY, RESOURCE EXPENDITURE, AND MOST ASSISTANCE NEEDED (N=41)

Condition	% with the reported diagnosis who state this condition is the:				
	% reporting condition	Most worrisome	Most time-consuming	Most costly	Requires most help ^b
All conditions combined (multiple morbidity)	100	34	27	12	10
Hypertension	93	8	16	13	5
Arthritis	78	28	53	22	19
Diabetes	44	39	44	39	33
Heart Disease	34	64	7	14	7
Cancer	27	10	—	20	—
Sensory deficits	12	—	20	20	—
Stroke	10	20	20	10	20
Bladder problems	7	33	33	—	—
Other	5	20	20	20	—

^a Conditions listed are the ones that participants considered most worrisome, time-consuming, costly, and requiring help. Other diagnosed conditions not appearing in this table include osteoporosis and allergies.

^b Only half of the sample (n=21) indicated that they received any informal help (family, non-paid caregivers) with their health condition. Help or assistance was defined by the participant and generally included such things as help paying for medicine or self-care needs, help with chores or functions made difficult because of their chronic conditions, and assistance with transportation to the pharmacy or doctors' offices.