Appalachian residents’ experiences with and management of multiple morbidity

Nancy E. Schoenberg¹, Shoshana H. Bardach¹,², Kavita N. Manchikanti³, and Anne C. Goodenow³

¹ Department of Behavioral Science, College of Medicine, University of Kentucky, Lexington, Kentucky
² Doctoral Program in Gerontology, College of Public Health, University of Kentucky, Lexington, Kentucky
³ College of Medicine, University of Kentucky, Lexington, Kentucky

Abstract

Approximately three quarters of middle aged and older adults have at least two simultaneously occurring chronic conditions (“multiple morbidity” or MM), a trend expected to increase dramatically throughout the world. Rural residents, who tend to have fewer personal and health resources, are more likely to experience MM. To improve our understanding of the ways in which vulnerable, rural residents in the U.S. experience and manage MM, we interviewed twenty rural Appalachian residents with MM. We identified the following themes; (a) MM has multifaceted challenges and is viewed as more than the sum of its parts; (b) numerous challenges exist to optimal MM self-management, particularly in a rural, under-resourced context; however, (c) participants described strategic methods of managing multiple chronic conditions, including prioritizing certain conditions and management strategies and drawing heavily on assistance from informal and formal sources.

Keywords
illness and disease, chronic; illness and disease, experiences; interviews; research, rural; risk, perceptions; self-care

The goal of this study was to improve understanding of how vulnerable rural residents experience and manage several simultaneously occurring chronic health conditions (“multiple morbidity” or MM).¹ Throughout the world, chronic conditions increasingly comprise the most burdensome health challenges, accounting for 60% of all deaths, particularly among middle aged and older adults (World Health Organization, 2010). For example, in the United States, Canada, and the Netherlands, approximately three quarters of those age 65+ have at least two chronic conditions (AHRQ, 2008; van den Akker, Buntix, Metsemakers, Roos, & Knottnerus, 1998), with one third of adults experiencing three or more chronic conditions in later life (Anderson & Horvath, 2002; Statistics Canada, 2010).

¹Consistent with Flaskerud and Winslow (1998), we conceptualize vulnerable populations as those “who experience limited resources and consequent high relative risk for morbidity and premature mortality.” (p. 69)
In the United States, the escalating prevalence of MM presents challenges to the economy, the health care delivery system and providers, and patients and their families. For example, 89% of the US Medicare annual budget is consumed by individuals with three or more chronic conditions, raising concerns about Medicare’s future viability (Center for Medicare and Medicaid Services, 2006). Multiple morbidity also presents numerous challenges to patients, including frequent interactions with the health care sector, substantial out-of-pocket health care expenditures, and complex (sometimes contradictory) self-management 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, and are more likely to have activity limitations and use more health services (Kane, Preister, & Totten, 2005; Lipscombe, Hux, & Booth, 2005; Starfield, et al., 2003). In the United States, individuals with two, three, and four co-occurring conditions sustained 41%, 85%, and 100% increases in out-of-pocket expenditures, respectively, over four years (Schoenberg, Kim, Edwards, & Fleming, 2007).

Although MM prevalence has not been specifically addressed in rural settings, there are several reasons why multiple morbidity is likely to exert a substantial burden on rural residents. First, the prevalence of chronic diseases, such as cancer, diabetes, arthritis, asthma, and heart disease among rural residents is higher than among other segments of the population (Eberhardt, Ingram, Makuc, Pamuk, & al., 2001; Murray, Kulkarni, Michaud, Tomijilma, & Bulzacchelli, 2006; Wingo, et al., 2008). Moreover, chronic conditions often cluster (e.g., metabolic syndrome) (National Heart Lung and Blood Institute, 2008). Lower income and educational attainment, factors highly correlated with poor health, are more pervasive among rural dwellers (Behringer & Friedell, 2006). Difficulty accessing needed health care services often arises due to lack of health insurance, competing financial demands, and inadequate knowledge or information. Lower income and educational attainment also is associated with adverse behaviors, including higher rates of tobacco use, less exercise, and less nutritious diets, which contribute to higher disease prevalence (Behringer & Friedell, 2006; Hartley, 2004). The health disadvantages that rural residents face are even more pronounced for residents of Central Appalachia who tend to be older and have fewer personal resources, leaving them vulnerable to worse outcomes (Behringer & Friedell, 2006).

Rural residents are also more likely to experience MM in resource-scarce environments, exacerbating the burden of multiple chronic conditions. On a community level, rural locations tend to have fewer health care professionals, particularly specialists; offer challenges related to the location (isolation, transportation barriers); and contain environmental factors that complicate health, such as lower water quality and extractive industry contaminants (Hartley, 2004).

Understanding how vulnerable rural residents with MM experience and manage their chronic conditions is a critical task. Although much of the existing literature on MM care focuses on formal medical management (Bayliss, Edwards, Steiner, & Main, 2008; Halanych, et al., 2007), 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 (Grey, Knafl, & McCorkle, 2006; Norburn, et al., 1995). Despite the importance of self-management, lay perspectives on MM self-management remain virtually unexplored (Bayliss, Steiner, Fernald, Crane, & Main, 2003; Clarke, Griffin, & Team, 2008). Particularly absent are those insights grounded in the lived experienced of individuals with multiple chronic conditions, and those that embed individual decision making in the context of community resources, social structure, and personal preferences (Thorne, Paterson, & Russell, 2003).
Theoretical Orientation and Methods

We employed a socioecologic framework to inform our instrument development and support a broad understanding and integration of findings. Using socioecologic frameworks allows researchers to move beyond a focus on the individual as a sole actor in the experiences of illness and self-management and acknowledge the influence of a broad array of social, economic, political, and environmental constructs and circumstances on health behavior and outcomes (Breslow, 1996; Brofenbrenner, 1979). Embedded within this broad model are several interacting layers of influence of individual experiences and health decision making (roughly corresponding to Rogers’ whole system approach of patient, professional, and structural influences). The patient or individual level includes a focus on macrosystems’ (cultural values) imprint on individuals’ experiences with MM and self-management approaches which we elicited through a modified series of anthropological ethnomedical questions (Kleinman, 1988; Schoenberg, 1997). Other lines of inquiry and analytic templates helped to elicit perspectives on how formal and informal interactions (microsystem) affect the MM experience and self-management orientations; mesosystem discussions focused on articulations between the health care system and work, church, etc; and other questions and discussion targeted the exosystem, or the broader social system in which an individual exists including the community’s economic basis (Brofenbrenner, 1979).

With this theoretical guidance, we developed a semi-structured and open-ended interview guide, refined the guide, and then interviewed rural middle aged and older adults from Appalachia. The interview guide was developed by a three stage process. First, to understand issues relevant to participants’ perspectives on MM, we engaged five women and men (ages forty or older with two or more MM) in traditional ethnographic interviews (Spradley, 1979), involving general domain discussion rather than specific questions about MMs. We revised the guide after pretesting with four new participants to ensure linguistic appropriateness, eliminate repetition, integrate overlooked issues, and minimize participant burden. Finally, we conducted our interviews with twenty Appalachian middle-aged and older adults from lower-socioeconomic status backgrounds with two or more MM. Those who engaged in the development of the interview guide were not eligible to participate in the main interviews.

Study Site

Region: Appalachia is a geographically and culturally diverse region of 410 counties in 13 states that contains nearly 22 million people, or 8.3% of the total US population. Appalachian Kentucky has socioeconomic status (SES) indicators among the lowest in the US, with poverty rates twice that of the national as a whole and the per capita income half the US average (Appalachian Regional Commission, 2006). County: The central Appalachian county, population: 25,000, in which the clinic is located is considered a persistent poverty, non metropolitan county (US Department of Agriculture, 2003). The county’s poverty rate is twice that of the nation as a whole and the per capita income is slightly over half the US average. Unemployment stands at 120% of the national rate. Educational attainment is significantly lower than national average; 58% and 7% of county residents have completed high school and college, respectively, compared with 80% and 24% nationally. (Appalachian Regional Commission, 2006). Clinic: All patients were recruited from a federally qualified health clinic in Appalachian Kentucky. The clinic provides primary care, laboratory, ancillary, and pharmacy services to 2,500 patients annually through volunteer and paid providers and referrals to other health and social service facilities. Referrals are made for specialty services, inpatient care, mental health care and substance abuse treatment.
Sample Eligibility and Recruitment Procedures

Our eligibility criteria included: age forty-one or over, diagnosis of two or more chronic illnesses; indicating 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-management (Lynch, Kaplan, & Salonen, 1997); and being able and willing to be interviewed. In addition to the widespread prevalence of MM among older adults, MM rates escalate among middle aged adults, particularly among those of lower socioeconomic status (Guralnick, 1996). Additionally, older age, rural residency, and being female exert particular challenges to maintaining health, given the higher likelihood that these groups lack adequate resources. Theoretical saturation dictated our sample size; saturation occurred after interviewing 18 individuals, but to enhance confidence in our findings, we conducted an additional two interviews (Strauss & Corbin, 1990).

Over the course of several months, our interviewer visited the clinic, sat in the waiting room until a receptionist quickly reviewed the patient’s chart to determine eligibility and then asked permission of the patient to make an introduction to our interviewer. The interviewer then verified eligibility via self-report, explained the study, and asked about a patient’s willingness to participate in an interview session. If the patient agreed, the interviewer would ask about a convenient time and location for the interview. Pressure to participate was mitigated by having the project interviewer rather than any clinic staff member invite participation. Although most patients agreed to be interviewed (20 out of 25), some patients refused outright and others were unable to be reached. Oftentimes, interviews were conducted immediately in a private interview room. Ethical approval was granted by our university’s Institutional Review Board, the governing research ethics committee for our university.

Interview Procedure and Protocol

At the first meeting, our interviewer read aloud the informed consent document, responded to any questions or concerns, and requested that the participant sign the document. The interviewer then asked participants the open-ended and semi-structured questions on life and health history and MM, including self-management strategies. With the approval of the participants, all interviews were tape recorded. Interviews lasted 45–90 minutes, depending on the participant’s loquaciousness and fatigue level. On completion, participants were thanked and provided with a $25 gift card. The provision of a gift card, standard in Appalachian research projects, was described after recruitment took place, thereby avoiding any potential coercion (Leach & Schoenberg, 2007).

Data Analysis

Data were analyzed using an iterative approach. After each interview, the tape recorded sessions were subjected to professional transcription. Three members of the research team reviewed each transcript as soon as it was transcribed, independently engaged in line-by-line coding, and regularly met to ensure similar coding orientations and to discuss themes and patterns. We initiated line-by-line coding rather than culling themes according to the pre-established template of the interview questionnaire. We compiled a codebook, defining and adding new codes, as needed, to refine it and to determine consistency within the line-by-line coding. Differences among the codes were reviewed and discussed until a consensus was reached (Strauss & Corbin, 1990).

Once the coding scheme and thirteen drafts of the codebook were completed, three coders pursued additional line-by-line and axial coding (Creswell, 1998) and clustered codes into conceptual categories and themes (Streubert-Speziale & Carpenter, 2003). Validation
checks, including assessing intercoder reliability and engaging in member checks, occurred throughout the analytic procedures, as did interpretation of results (Jette, 2002). This iterative process of coding, sharing codes, debating concordant codes, and re-coding was repeated until we ultimately established an intercoder reliability ratio of .80 (Patton, 2002), generally considered an acceptable degree of agreement among coders (Bernard, 1998). We did not use any computerized qualitative data analysis packages.

Results

Consistent with our eligibility criteria, our sample ranged from 41 and older years of age (mean: 55); had an average of four chronic health conditions (self-reported), including heart disease or hypertension (90%), arthritis (80%); type 2 diabetes (75%), cancer (10%), stroke (10%), and numerous other illnesses (65%). Most reported their health as poor (40%) or fair (45%), with 15% self-assessing their health as good. Consistent with the central Appalachian region, our sample was mostly White (95%); had relatively modest levels of education (15% had less than a high school education; 25% attended some high school; 55% earned a high school diploma or GED; and 5% had some post secondary education); and was poor (65% reported an annual household income of less than $10,000; 20% reported $10,001–15,000; 5% between $15,001–20,000; and 10% indicated incomes between $20,001–25,000). Eighty-five percent indicated that they struggled to get by, and none of the participants was currently employed. Most (70%) had no health insurance; those who did indicated Medicaid, Medicare, or disability coverage. The average length of residence in the county was 36 years. Most participants were female (85%), were married (55%); lived with at least one other person, and had an average of three children.

We identified several core themes on Appalachian residents’ experiences with and management of MM focusing on the most salient and predominant themes.

(a) Multifaceted challenges of MM—more than the sum of parts

Participants drew on their previous health experiences, and knowledge to view MM as more than the sum of its individual conditions. The confluence of conditions offered unique challenges including worry over negative health consequences and conflicting and confusing treatment. Although a 59-year-old initiated his discussion of major health concerns with fear about diabetes complications, he quickly transitioned into describing a number of worrisome chronic conditions:

I worry about the diabetes more than I do anything when they start talking about how you lose your toe first and then your foot and then your leg, that’s what I worry about that more than every one of them. But I worry about blood pressure too. They said it could cause a stroke or a heart attack and stuff and put you in a wheelchair the rest of your life. If you have a bad stroke, it might take you out. I worry about all of them. You’ll worry about all of them some time or another; it’ll be on your mind. It’s hard not to.

Like this participant, a 56-year-old female indicated that she is preoccupied with her diabetes but also feared that problems with her diabetes would lead to a worsening of other conditions. “I know what complications you can get from it (diabetes). And it contributes to the heart disease and the arthritis and the high blood pressure…”

Some participants expressed concern that the treatment for one condition might be detrimental to another condition, especially in meeting dietary and medication requirements. This concern derived from participants’ own interpretation of medical advice rather than from their physicians’ recommendations. Indeed, participants expressing this concern tended to view their health conditions, rather than the physician’s advice, as vexing. A 46-year-old...
woman with diabetes, hyperlipidemia, and hypertension expressed her frustration at what appeared to her to be conflicting management orientations: “If you try to treat the blood pressure, then the sugar will go up. Because what you eat with the blood pressure is not always good on the sugar.”

Others expressed concern about taking several medications simultaneously because of possible side-effects, conflicting regimens, difficulty with recall, and the need for correct timing of numerous medications. A 57-year-old woman described, “Well you have to keep up with what time you have to take this medicine and that medicine…and sometimes they react against each other…so you have to take them at different times.” The sheer number of medications required to treat her MM challenged a 49-year-old woman suffering from hypertension, arthritis, hyperlipidemia, and depression: “Sometimes I forget (my medicines) and I think, ‘well did I take that today?’ I have to sit and think if I took that or not and then you’re afraid to take it.” She explained that her depression in particular made it difficult for her to be proactive in her medication management, that she “sometimes is in a fog.” On a bad day, she explained, the depression undermines her ability to stay on track with her other medications and management.

(b) The role of community context and cultural values in self-management

Like the confluence of MM themselves, participants described how community conditions—including scarcity of personal resources, inadequate transportation to healthcare appointments, pervasive health care provider shortages, and insufficient “healthy” resources—undermined self-management. A 50-year-old man with hypertension, arthritis, hyperlipidemia, and diabetes, attributed two heart attacks to his inability to afford medication before finding the federally qualified health clinic:

Without this place [the clinic], I wouldn’t be able to have Plavix. And the last two heart attacks I’ve had, they’ve both been when I couldn’t afford the medication.

And after about two months off my Plavix and the others, I ended up having a heart attack.

In a location where many jobs depend on physically exerting activities (logging, mining, small scale manufacturing), multiple chronic illnesses often resulted in inability to keep a job, taking a toll on financial resources. A 57-year-old woman with arthritis, thyroid disease, depression, and Chronic Obstructive Pulmonary Disease (COPD) described her experience of giving up her factory job because of her MM. This job, one of the few available in her distressed county, provided both financial solvency and a sense of purpose. Despite the high unemployment rate in both the community and among participants, many bemoaned how a core cultural value of hard work was hard to live up to with MM. “When you’re used to working and then something just hits you all of a sudden and you can’t do it no more, it’s like your life is over.” Her replacement was hired within 48 hours and she lost her health insurance and her stable income, and now has a hard time affording her over the counter medication. Inability to live up to this deep seated cultural expectation of hard work was especially difficult for men to accept. A 50-year-old man expressed the financial and emotional strain of dealing with his conditions: “I go through depression and stuff, I’m going through it now but sometimes I just think it’d be better if I just have a heart attack and die. It’d be easier on my wife and stuff financially.”

Inadequate transportation, health care provider shortages, and insufficient healthy resources presented great challenges to implementing demanding self- and formal management. In the economically distressed counties of Appalachia, residents are nearly twice as likely to live in a household without a vehicle as in other non-metropolitan regions of the United States (Appalachian Regional Commission, 2004). This is especially challenging given the near absence of public transportation. Making an average of six visits to the clinic per year,
participants who lacked reliable transportation struggled and had to choose between paying a local resident for a ride; relying on the goodness of friends and relatives; walking steep and winding roads traversed by logging and coal vehicles; or, if fortunate enough to have the option, scheduling (and paying for) one of the rare public transport services. One participant traveled twice a month, two hours each way, to get to the clinic. She had a car “but sometimes it breaks down on me and I have to get someone to bring me.” She noted that she doesn’t have many drivers available; she relies on her ex-husband whom she divorced 13 years ago.

The options for accessible and affordable health care in rural central Appalachia similarly are limited. The two, three, or four hour one way trips to the free clinic recounted by many participants highlighted the scarcity of providers. Specialists, frequently needed by those with MM, were in particularly short supply, requiring patients to wait many hours or do without. Despite waiting for hours to see a cardiologist, a participant lauded the free clinic “… they’ve (the clinic) got a heart doctor that comes in once a month. He donates his time once a month to see people like me.” Participants often described their providers in glowing terms, appreciative for the few services that they can obtain.

Finally, participants described an environment bereft of healthy resources that would enhance their MM self-management. Such resources included mental health counseling, grocery stores with affordable, fresh produce, and exercise facilities. For example, a participant with diabetes, hypertension, and dyslipidemia, noted that the lack of accessible mental health services made it difficult to control her depression which, in turn, negatively affected her ability to maintain a healthy lifestyle:

And then like some days, I don’t want to see anybody, I don’t want to talk to anybody, it’s one of those days where I feel like the world’s against me and I just want to die … (on those days I) Lay in the bed and shut the door, I don’t see nobody.

Lacking the energy to get out of bed, she avoided exercise, social interaction, and food preparation. She estimated this situation occurs twice weekly, and noted she is unable to get her mental health needs met where she lives.

(c) Strategies of MM self-management

Participants attempted to reconcile their physicians’ recommendations with their constrained life circumstances in several ways. First, although most participants praised their providers and acknowledged the importance of their recommendations, they described settling into a management routine often at odds with biomedical recommendations, but ones that worked for them. One participant, age 60, described her many efforts over the years to manage her diabetes, hypertension, and arthritis, noting the arthritis makes it difficult to do the physical activity advocated by her doctor. Her experiential MM regimen included careful adherence to her prescriptions and a special chair exercise she developed to provide some exercise without exacerbating joint pain, allowing her to “keep my heart strong and my sugar ok.” As this and many other participants indicated, most MM self-management appeared to focus on using prescriptions rather than implementing major lifestyle changes. A 46-year-old participant noted that although her doctor has advised that losing weight and getting exercise would help with all of her conditions, she “mostly just takes the pills now.” Although not unique to Appalachian residents, lack of engagement in exercise for MM management was often described as a cultural issue. Having engaged in vigorous physical labor on farms or in mines has led to a lack of tradition of intentional physical activity.

Additionally, relegating some illnesses to a more secondary position allowed people to expend fewer resources on these conditions, a helpful strategy for those lacking material,
time, or psychological resources. Some conditions appeared more salient and concerning than others due to family history or to perceived seriousness or symptoms. A 62-year-old woman with high blood pressure, arthritis, cancer, and diabetes explained that she gave more attention to her diabetes because: “I’ve had too many in the family with diabetes and my dad was a diabetic and it contributed to his death. And my aunt, she was real close and she had it really, really bad.” A 56-year-old with diabetes, heart disease, high blood pressure, degenerative bone disease, and congestive heart failure, prioritized diabetes “because it affects all parts of your body including your brain, because it affects the blood vessels and your whole body.” A 65-year-old with Wolff-Parkinson-White syndrome and COPD prioritized her COPD because “You get to smothering so bad when you get up to start trying to move you have to hold on in order to get from one place to the other one.” In her attempts to avoid this sensation and activity limitations, she described focusing on taking her bronchodilator medication, and using the breathing exercises she was given, saying even “if I don’t do nothing else—I try to do that.”

Another coping strategy for rural, under-resourced people with MM involved receiving help from formal sources, including the free clinic and health department (information, support services, and medication/equipment samples for MM management). For example, a participant noted that the clinic provided his medications: “If they didn’t, I don’t know what I’d do.” Another patient, who has utilized the clinic for twelve years, said, “They make sure I have all my medicine and my insulin and my needles and everything I need like that.” Unfortunately, the clinic is unable to provide everything for everyone and some participants cited problems paying for glucose strips, heating pads, or over the counter medications. Others relied on a combination of formal and informal assistance. A 57-year-old woman suffered from arthritis, blackout spells, depression, thyroid problems, and asthma, forcing her to quit her job at Wal-Mart. With little money available to pay for her extensive list of medications, the participant relied on available assets—the clinic and her kin. She received most of her medications on a sliding scale from the clinic and relied on her daughter to cover the remaining costs. A 50-year-old retiree who recently returned to Kentucky from Ohio described the informal and formal support he has received to assist with his diabetes, hypertension, high cholesterol, and three major heart attacks in the past six years. His wife helped him with the complicated dietary management of his multiple chronic conditions, while the clinic assisted with medications and specialist referrals. He stated that:

Without places like this clinic here…that’s been a godsend for people like me. Up there in Ohio, I couldn’t get no help. No help whatsoever and that’s another reason why we come down...here because we know that down here in Kentucky, they take care of their people.

For others, making ends meet revolved completely around the receipt of informal support, generally from spouses, siblings, children, and grandchildren. Following well-established cultural traditions of involving informal supports, participants described efforts that leverage a feature characteristic of Appalachia-- dense social networks built on stable residence patterns. Emphasis was placed on family members to meet needs including housekeeping when disability precluded upkeep; information sharing and advice; and extensive financial assistance. As another participant reflected:

We don’t have much in the mountains. But we have kin. We always have had kin. Plenty of kin around. You look this hollow and in town and you’ll hear the same family names. If you’re a (common Appalachia surname) you’re probably kin to me. And if you’re kin to me, you’re probably going to wind up helping me get somewhere, buy those pills, you know.
Discussion

Although this is the first known study to examine the experiences of vulnerable rural residents as they manage multiple health conditions, this study was not without its limitations, including a modest sized sample, geographically distinct study site, recruitment at a single (and conventional health care) location, and some omissions in data collected. Previous research has demonstrated that if studies are conducted among a relatively homogenous group of individuals, sample size can be small and remain robust (Guest, Bunce, & Johnson, 2006). Recruiting from a federally qualified health clinic might have resulted in involving participants with a more biomedical orientation and those who have successfully accessed medical services. However, to ensure recruitment of individuals with low socioeconomic status who have MM, we necessarily employed such a recruitment venue. Finally, there were limitations in our data collection efforts. For example, we did not specifically inquire about specific medication management for participants with diabetes. It is quite possible that those individuals who treat their diabetes with insulin may prioritize diabetes for fear rapid onset of complications if they did not closely adhere to the recommended medication regimen. As this article is a first effort in describing MM management among rural residents, we necessarily were judicious in our selection of themes, presenting the most salient descriptions at the expense of exploring numerous subthemes.

Despite these limitations, this article highlights a seldom explored, but increasingly important health care issue-- multiple morbidty and the challenges of self-management in vulnerable populations. Experiencing MM and meeting recommended self-management practices was shaped by challenges and opportunities originating from a broad socioecological context, including an individual’s particular situation (macro and microsystems—e.g., health beliefs, personal resources, cultural values); informal (e.g., kin) and formal (e.g., clinic) factors (microsystems); and structural (e.g., community resources) (meso and exosystems) issues in the environment (McLeroy, Bibeau, Stechler, & Glanz, 1988; Rogers, Kennedy, Nelson, & Robinson, 2005).

Macro and micro system factors intersect to structure the daily experiences of MM self-management, as individuals with multiple morbidities sought to establish a fit between their everyday lives, their priorities (survival, freedom from symptoms), and values (independence, work, family) and what they considered legitimate and expert knowledge of health care professionals, reinterpreting, contesting, and trying to live up to such advice (Clark & Gong, 2000). In partnership with providers and significant others, people with MM must wade through complex and sometimes contradictory self-management recommendations. Baptist and colleagues (2010) found that considerable confusion over complex symptoms and management approaches emerged among older patients with asthma, sometimes leading to experimental self-management. In the words of one focus group participant, “The symptoms are basically the same. It’s like try this, try that, try your blood pressure pills.” Because such experiential and experimental self-management orientations apply to that single disease, MM self-management must be considered exponentially more complicated. Indeed, studies have demonstrated an inverse relationship between greater number of self-management activities and adherence to medical recommendations (Cramer, 2004).

Compounding this complexity, participants in our study and other under resourced communities often experienced conditions and treatment burdens that exceeded their personal and resource capacities, resulting in constrained choices. Not only did participants mention direct challenges to self-management including paying for medications, but they also described indirect, opportunity costs (for example, forced retirement) of illness.
At the same time, participants demonstrated remarkable resourcefulness, resilience, and strategic planning involving drawing on all systems levels to normalize their lives. For example, participants prioritized one illness over another, allowing them to conserve resources for those conditions they deemed more critical. Consistent with the limited existing research, participants explained that several factors shaped prioritization of a particular condition, including perceived severity of an illness; the limitations, complications, and symptoms that it might cause; and their own familiarity with negative outcomes (Dorr, Wilcox, Burns, Narus, & Clayton, 2006; Nutting, et al., 2007; Siminerio, Piatt, & Zgibor, 2005; Smith & O’Dowd, 2007). Similarly, after years of experience with MM management, participants emphasized certain management strategies (e.g., medication taking) that seemed most helpful to them. Although this prioritization may be necessary in resource scarce communities, MM patients run the risk of overlooking other essential conditions and management tasks which should be coordinated with health care professionals (Schoenberg, Leach, & Edwards, 2009). At the same time, health care providers run the risk of assuming that, after providing extensive information on and supportive care for self-management, patients’ orientations will be committed to biomedical recommendations rather than constrained or otherwise responsive to the daily conflicts and compromises of complex management (Thorne, et al., 2003).

Another means by which participants sought control over their MM was by drawing on support from micro and meso system factors, or informal and formal interactions. Informal supportive others played a significant role in facilitating MM self-management. Although social support has been shown to be beneficial to health (Tomaka, Thompson, & Palacios, 2006), there are few, if any, published findings on interventions for those with MM. Extrapolating from social support intervention successes among those with single chronic condition (Taylor, et al., 2004; van Dam, et al., 2005), and other examinations of chronic care models (CCMs), it seems logical to leverage the strong family traditions of Appalachian and other rural residents (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Walker, Epstein, Taylor, Crockers, & Tuttle, 1989). Participants corroborated existing literature that emphasizes the responsibilities and inextricable connections of kin relations in central Appalachia; like many traditionally underserved populations, blood ties have been among the only reliable support in an otherwise resource disadvantaged environment (Keefe & Greene, 2005).

Participants’ appreciation for the few existing medical resources they have lends promise to management approaches like enhanced counseling, medical case management, motivational interviewing and collaborative goal setting for complex MM management negotiation (Sevick, et al., 2007). These counseling approaches can be undertaken by a range of trained individuals, including physicians, nurses, certified diabetes educators, and trained counselors. Such staffing flexibility is critical in a rural health care delivery environment with chronic health care provider shortages (Coughlin, Leadbetter, Richards, & Sabatino, 2008). Rural community health centers, like the clinic in this study, tend to have a significantly higher proportion of non-physician staff, many more vacancies, and longer term vacancies (Rosenblatt, Andrieu, Curtin, & Hart, 2006).

In addition to this type of meso structural resource, exosystem approaches should be considered to enhance MM management for vulnerable patients. Such approaches include implementation of chronic care models (CCM) (Wagner, et al., 2001), which leverage the interaction among various actors and entities--patients, providers, family members, social services, and other community resources and focus on health system, community, decision
support, self-management support, clinical information systems, and delivery system design (Epping-Jordan, Pruitt, Bengoa, & Wagner, 2004). CCM orientations involve more in-depth and time consuming consultations and offering auxiliary support services, including referrals to professionals, provision of medical resources, and decision support for health education programs. Lorig and colleagues’ (Lorig, et al., 1999) Chronic Disease Self-Management Program is comprised of dimensions that are well suited for MM management.

Less certain is whether the program can be applied to vulnerable rural populations in the United States with complex medical issues. Few programs using CCM have been applied to rural patients with MM, with the closest approximations including those focused on a broader regional population (Dorr, et al., 2006) or on certain conditions (Siminerio, et al., 2005). Siminerio and colleagues (2005) demonstrated the feasibility and utility of implementing CCM elements decision support, self-management education, and delivery system redesign into a rural practice site. After a year, providers demonstrated greater adherence to diabetes practice guidelines and patients improved their diabetes knowledge, sense of empowerment, A1C, and high-density lipoprotein cholesterol levels. Nutting and colleagues (2007) also have shown that implementation of the CCM in small, primary care practices is feasible and improves diabetes outcomes. Apart from the clinic, community health workers offer promise in addressing MM management (Black, 2007; Smith & O’Dowd, 2007). Programs in the United States that provide medical case management have shown encouraging outcomes, including the Kentucky Homeplace Program (KHP) (Schoenberg, Campbell, Garrity, Snider, & Main, 2001). In addition to coordinated and integrated care approaches, patient-centeredness and shared decision making might hold promise for enhanced self-management if patients’ experiences and practices can truly be integrated into the care plan (Clark & Gong, 2000).

Such structural or meso and exosystemic contexts offer challenges to optimal MM experience and self-management practices. Our findings will resonate with other severely under resourced regions, especially those highlighted in Murray and colleague’s article, “Eight Americas;” (Murray, et al., 2006) however, study participants appeared to experience an extreme version of the challenges others cope with; high rates of poverty, low levels of education, unemployment, and lack of health insurance. For example, Hendryx (2008) found that 70% of Appalachian nonmetropolitan counties could be considered mental health professional shortage areas, significantly higher than non-Appalachian, rural counties and corroborating our participants’ concerns about managing illness in the face of depression.

However, rather than simply focus on the deficiencies and challenges, as participants pointed out numerous times, there are substantial assets to support MM management. Such assets include microsystem issues like kin support; macros system factors like cultural values of independence and hard work; and meso and exosystem level supports including the federally qualified health clinic systems, local health department programming, and medication assistance programs. Identifying these assets and implementing supportive programs or approaches requires significant creativity and effective use of existing resources, approaches familiar to lower SES populations like those in Appalachian Kentucky (Halperin, 1990).

Our findings demonstrate that experiencing and managing MM, especially among extremely vulnerable populations, is a complex task that defies extrapolation from single disease self-management studies. In-depth and grounded perspectives on MM self-management should be expanded to provide generalizable data that will inform the development of effective programs and policies. Given the escalating trend of multiple morbidity, bold first steps are required to forge a path of effective coordination and management, particularly among those populations at greatest risk from co-occurring illnesses.
Acknowledgments

This research was supported by funding through the Department of Behavioral Science at the University of Kentucky College Of Medicine and through a grant from the National Cancer Institute (R21 CA129881)

References


Kane, RL.; Preister, R.; Totten, A. Meeting the challenge of chronic illness. Baltimore: Johns Hopkins University Press; 2005.


Norburn JER, Bernard SL, Konrad TR, Woomert A, DeFries GH, Kalsebeck WD, et al. Self-care and assistance from others in coping with functional status limitations among a national sample of

*Qual Health Res. Author manuscript; available in PMC 2011 May 1.*
Streubert-Speziale, HJ.; Carpenter, DR. Qualitative Research in Nursing: Advancing the Humanistic Imperative. 3. Philadelphia: Lippincott Williams & Wilkins; 2003.


Biographies

Schoenberg is a professor in the Department of Behavioral Science at the University of Kentucky’s College of Medicine. Her interests focus on health inequities, prevention and control of chronic conditions, and community-based, participatory research.

Bardach is a student in the Doctoral Program in Gerontology at the University of Kentucky.

Manchikanti is a third year medical student at the University of Kentucky.

Goodenow is a third year medical student at the University of Kentucky.