The Meaning and Significance of Self-Management Among Socioeconomically Vulnerable Older Adults

Daniel O. Clark,[1,2,3] Richard M. Frankel,[2,3,4] David L. Morgan,[5] Gretchen Ricketts,[1,2] Matthew J. Bair,[2,3,4] Kathryn A. Nyland,[4] and Christopher M. Callahan[1,2,3]

[1]Indiana University Center for Aging Research, Indianapolis.
[2]Regenstrief Institute, Inc., Indianapolis, Indiana.
[3]Division of General Internal Medicine and Geriatrics, Department of Medicine,
Indiana University School of Medicine, Indianapolis.
[4]Richard L. Roudebush VA Medical Center, Indianapolis, Indiana.
[5]Department of Sociology, Portland State University, Oregon.

Objectives. The aim of this study was to describe and contrast perceptions of self-management among socioeconomically vulnerable and nonvulnerable older adults.

Methods. We used in-depth, in-home interviews guided by identity theory. Analyses included reviewing audiotapes, creating and comparing field notes, coding transcripts, and identifying themes based on case summaries. Interviews took place in patients' homes. Participants were 23 vulnerable older adults with incomes at or below 200% of the federal poverty level and no private insurance and 12 older adults with private health insurance.

Results. The vulnerable sample had lower educational attainment and lower health literacy than the privately insured sample. Keeping doctor visits and taking prescription medications largely defined self-management for the vulnerable sample but were just two of a number of roles noted by the privately insured group, who expressed health promotion as the key to healthy aging. The vulnerable interviewees relayed few examples of healthy aging and did not have expectations for healthful aging. In contrast, the privately insured interviewees gave examples and had expectations of living long and healthfully into old age.

Discussion. Improved understanding of the role of social context in expectations regarding aging, and awareness of and priorities for self-management, could lead to improvements in self-management support and thus chronic care outcomes.

Key Words: Self-management—Health literacy—Qualitative research—Health disparities.

SELF-MANAGEMENT is critical to improvements in chronic care. A recent Institute of Medicine (2003) report identified self-management as a top priority for the U.S. health system. The Centers for Disease Control and Prevention (2007) *State of Aging and Health in America Report* also set self-management as a top priority, with six of its seven calls to action having self-management as a central pathway. Models of effective chronic illness care have at their center patients who are informed, active self-managers (Bodenheimer, Lorig, Holman, & Grumbach, 2002; N. M. Clark, Gong, & Kaciroti, 2001). Unfortunately, many chronically ill older adults have limited access to the resources necessary for being informed, active self-managers. It has been estimated that up to one third of chronically ill older adults are *socioeconomically vulnerable*, defined as having low income, low education, and/or low health literacy (D. O. Clark, Stump, Miller, & Long, 2007; Morrow et al., 2006). We report here on interview data that compare self-management awareness and priorities of vulnerable and nonvulnerable older adults.

Self-management includes both provider- and patient-initiated behaviors (or lack thereof) intended for illness treatment and health maintenance (Corbin & Strauss, 1988; Dean, 1986; Ory & DeFriese, 1998). Self-management support is the provision of education and support to increase patients'

skills and confidence in managing their health and illness (Institute of Medicine, 2003). To date, few interventions intended to improve self-management have achieved the desired outcome (Chodosh et al., 2005). Our own randomized trials involving vulnerable older adults have indicated that self-management is often a weak, yet critical, link in collaborative care programs (Callahan, 2001; Counsell, Callahan, Buttar, Clark, & Frank, 2006). A greater understanding of the life meaning and lived experiences of vulnerable older adults may be needed to better tailor self-management support to the individual. Bodenheimer (2007) recently published five steps to evidence-based chronic care medicine. The final step is helping patients incorporate self-management into their daily lives. This, he wrote, requires getting to know the patient so that a truly collaborative plan for self-management can be developed.

Getting to know the patient in order to improve self-management support will likely require a greater knowledge of the patient's self-management resources, expectations, awareness, and priorities. Fortunately, some important tools have been developed recently. For example, Glasgow, Strycker, Toober, and Eakin (2000) have developed the Chronic Illness Resources Survey, and Hibbard, Stockard, Mahoney, and Tusler (2004) have developed the Patient Activation Measure. The multilevel Chronic Illness Resources Survey focuses on

resources for self-management, and the Patient Activation Measure assesses knowledge and self-efficacy. Both were developed to be relevant across chronic illnesses.

Expectations for aging have also received attention. Expectations represent what one thinks is probable. Sarkisian, Prohaska, Wong, Hirsch, and Mangione (2005) have developed a survey of expectations regarding aging that measures the extent to which people feel that aging is accompanied by undesirable and inevitable social, psychological, and physical consequences. The authors showed that persons with low expectations were 2.6 times more likely to report physical inactivity than persons with high expectations, an indication that general aging expectations are related to self-management behavior.

In addition to resources and expectations, researchers hypothesize that a certain level of task awareness and priority is necessary for self-management (Baranowski, Perry, & Parcel, 2002; Bellg, 2003; Ryan & Deci, 2000). N. M. Clark (2003) has presented a self-regulation model of chronic illness self-management that is based on Bandura's (1986) popular social cognitive theory. The self-regulation model describes a continual, behavior-specific process of goal setting and self-monitoring based on experience, observation, judgment, outcome expectations, and self-efficacy. *Self-efficacy* is the most frequently applied concept of social cognitive theory and is defined as confidence in one's ability to perform a specific behavior. Self-efficacy predicts behavior best when the anticipated outcome is relevant and of high value (i.e., a priority; Baranowski et al., 2002).

Getting to know a patient or patient population in regard to these self-management factors is likely important to improved self-management support and ultimately chronic illness care. To date, there has been important empirical and theoretical work on these self-management factors (e.g., Lorig et al., 2001). As valuable as this work is, there may remain a knowledge gap between the concepts and the lived experiences of vulnerable older adults. These adults have limited resources and may face particular life contexts that affect awareness, expectations, and priorities for self-management. Our goal in this project was to engage in in-depth conversations with a sample of low socioeconomic status, low health literacy older adults with multiple chronic conditions to better understand their self-management knowledge, resources, expectations, and priorities. Because little is known about the particular challenges faced by these individuals, we reasoned that discovery-oriented interviews would give us a greater understanding of the value and relevance of particular self-management behaviors and provide insight into self-management priorities and motivation (Bellg, 2003; Ryan & Deci, 2000). This, in turn, would improve our ability to reach vulnerable older adults through more appropriately tailored programs and potentially elevate the depth of understanding that providers may achieve about their vulnerable older patients.

We drew on prior, unstructured pilot interviews and elements of identity theory to guide the development of our interview script. Identity theory asserts that roles and activities felt to be most critical to maintaining a sense of importance are selected and optimized, and behaviors regarded as critical to those roles and activities are thus a priority (Schulz & Heckhausen, 1996). We present themes identified from in-depth, home-based interviews comparing two samples of urban-living older adults: one with average education and health literacy and one with lower education and health literacy. Based on our own intervention work with socioeconomically vulnerable older adults and persistent evidence of a socioeconomic gradient in health and health behavior (House, Lantz, & Herd, 2005), we hypothesized that there would be differences between these two groups in self-management priorities, awareness, and expectations.

METHODS

Sample

We recruited participants to be interviewed from two separate lists of persons 65 years of age or older who had visited one of two primary care groups in Indianapolis, Indiana, within the past 12 months. A practice-based research network with recruitment offices in primary care sites serving a largely socioeconomically disadvantaged patient population and recruitment offices in sites serving a largely advantaged patient population made Indianapolis a good location for this work. We generated a sample list from a city–county health system serving a primarily publicly insured, socioeconomically vulnerable population and a list from a comparison system that serves a primarily nonvulnerable, privately insured population. Most city–county patients are under- or uninsured, and most private clinic patients have some form of private supplemental insurance. Both health systems are staffed by Indiana University School of Medicine faculty and residents and use an electronic medical records system. We built sampling lists from the medical records data, and we included only persons with private supplemental insurance on the private clinic sample list and only patients eligible for the local indigent health plan on the city–county sample list. Patients had to have a household income of less than 200% of the federal poverty level to be eligible for the indigent health plan. All participants had comorbid chronic illnesses, the most common being hypertension, asthma, and diabetes. We recruited quota samples of men and women and non-Hispanic Blacks and Whites from each list. All but 1 of the 36 recruited patients consented and completed a semistructured qualitative in-home interview. Our particular interest was in the vulnerable city–county group; thus, we obtained a larger sample and completed more interviews in that group ($n = 23$ vs $n = 12$ in the private sample).

We included a sufficient number of interviews with women and men and Blacks and Whites in each sample to ensure representation. Seidman (1998) stated that the ''sufficient'' number of interviews cannot reasonably be set and depends on population representation. We did not focus on determining differences between men and women or between Blacks and Whites, but rather we were concerned about representation in each sample. We set a goal of three interviewees in each subgroup within each sample but erred on the side of too many interviews in our vulnerable sample. We completed interviews with a total of 12 Black women, 7 Black men, 7 White women, and 9 White men. In each race-by-gender group, three interviewees were from the private health system.

We recruited interviewees by telephone or approached them during clinic visits. We informed potential study participants that they were being selected for a one-time interview to discuss their experiences in managing their health. We conducted interviews at an agreed-upon time in the interviewee's home.

Upon completion of the interview, interviewees received $40 cash compensation. The Indiana University Purdue University–Indianapolis institutional review board approved the study.

Interview Content

We used the interview method, as it is well suited to obtaining in-depth subjective data (Seidman, 1998). Our approach was phenomenological in nature, as we were attempting to understand the experience and meaning of self-management for vulnerable older adults. We did not approach our problem "deconstructed," or without preconceptions, as some have recommended in qualitative research. Rather, having completed earlier unstructured pilot interviews and having reviewed various theoretical traditions, we entered this work with the view that identity and a sense of importance to others are critically important. Thus, our interview was informed by identity theory (Stryker, 1968), particularly the concepts of importance and interdependence (Rosenberg & McCullough, 1981). Maintaining a sense of importance or sense of mattering to others (Taylor & Turner, 2001) is a prime human motivation (Pearlin, 1999), and roles and activities felt to be most critical to maintaining a sense of importance are selected and optimized (i.e., guarded from loss) more than others (Schulz & Heckhausen, 1996). Behaviors regarded as critical to those most important roles and activities would thus be a priority.

The interdisciplinary research team included a physician-researcher with expertise in geriatrics and in designing chronic care models, a medical sociologist with experience in interventions to improve lifestyle behaviors, a sociologist with experience in patient–provider communication and qualitative analysis, and a social worker with experience in providing in-home interventions. The team developed a draft script, and four different team members conducted pilot interviews in patients' homes. Each team member reviewed audiotapes of pilot interviews with the goal of identifying the questions and probes that yielded life meaning and priorities; health expectations; and self-management awareness, resources, and practice.

We began the interview by asking general questions about the roles that were most important to the interviewees and which activities and expectations they felt were a part of their most important roles. Having obtained information on role identities, the interviewer asked interviewees to list specific self-management behaviors they practiced, recommendations they would have for others, and how they felt these practices relate to their role activities and expectations. We specifically asked patients whether their conditions or management activities affected their ability to carry out their role activities and role expectations. The final interview had four main sections: (a) getting to know the person, (b) chronic health conditions and their effect(s) on activities and roles, (c) life meaning and priorities, and (d) self-management strategies. It is important to note that we did not put limits on or define self-management activities for patients. The Appendix shows the full interview script.

In-Home Interviews and Data Collection

A Black male and White female research assistant conducted the approximately 1-hr in-home interviews. Some interviews were completed with a White male investigator also present. At the completion of the interview, we determined a health literacy

Table 1. Sample Characteristics by Sampling Source

Characteristic	Vulnerable ($n = 23$)	Nonvulnerable ($n = 12$)
Mean age	72.1	72.1
Race-by-gender distribution		
Black women	9	3
Black men	4	3
White women	4	3
White men	6	3
Education distribution		
8 years or less	3	0
9–11 years	6	3
12 years	5	2
13 or more years	9	7
M REALM-R (0–8)	4.7	6.8

Note: Scores on the REALM-R range from 0 to 8, with a lower score indicating lower health literacy. One Black woman in the vulnerable sample did not complete the REALM-R. REALM-R = Rapid Estimate of Adult Literacy in Medicine.

score by using the Rapid Estimate of Adult Literacy in Medicine (REALM-R; Bass, Wilson, & Griffith, 2003). We also recorded years of formal education, gender, age, and ethnicity. We used all of this information in the analysis of the two interview groups.

Qualitative Analysis

We continuously collected, organized, and interpreted data throughout the project to arrive at themes regarding self-management (Morgan, 1993). We audiotaped, transcribed, and analyzed more than 40 hr of interview time. Each member of the research team listened to the audiotapes and completed an initial independent analysis. As outlined in Morgan, analyses included listening to the audiotapes, making notes to capture key observations, coding transcripts, and completing a written summary of each case. We shared the summaries and discussed them in regular research meetings. Consensus was not the goal of these meetings. Rather, concepts and postulates were presented by the team members, discussed, sometimes debated, and recorded consistent with the differing perspectives of the interdisciplinary team.

After the coding of several sets of interviews using NVivo software, a consensus emerged among team members that coding items across cases was not deepening our understanding of the uniqueness of each individual interview. We found that, in order to preserve the individual as the unit of measure, listening to the audiotapes and writing case summaries from which we could extract themes was particularly valuable. Creating discussion around the summaries, allowing differences of finding within our discussions, and giving weight to ideas that occurred infrequently in the interviews facilitated our discovery-oriented, contextually sensitive approach. In continually reviewing and summarizing our data and discussions, we identified four themes, which we present below.

RESULTS

Table 1 compares data for the vulnerable ($n = 22$) and nonvulnerable ($n = 12$) samples. Mean age was the same for the two samples. Education was different at the low end; 40% of the

vulnerable sample did not complete high school versus 25% of the nonvulnerable sample. Health literacy was also lower in the vulnerable compared to the nonvulnerable sample (4.7 vs 6.8). Excluding the three vulnerable interviewees with 8 or fewer years of education only increased the REALM-R mean to 4.9 in that group. A score of 6 on the REALM-R corresponds to a sixth-grade reading level, below which individuals would have difficulty understanding medical instructions (Bass et al., 2003).

We identified vulnerable and nonvulnerable sample differences in four main areas in the semistructured qualitative interviews: (a) prescription medications and health care, (b) caring for family members, (c) health promotion priorities, and (d) expectations about health and aging.

Prescription Medications and Health Care

Medication resources.—Most individuals in the vulnerable sample reported difficulty affording their medication copayments. These were typically $5 per medication, but with multiple medications this copayment could approach $50 or more per month for an individual patient. In the vulnerable sample, medications and sometimes food were insufficiently available due to a lack of financial resources. One individual in the vulnerable sample, a retired chef, had good health literacy but was nonetheless quite poor. He stated, "I have a period. I don't have that kind of period but I do have a financial period. I eat better at the beginning of the month." Despite financial difficulty and limited knowledge of prescription medications, few in this group reported adherence issues, and most all used some sort of medication schedule reminder, such as a pillbox.

Medication knowledge and role.—Interviewees in the vulnerable sample often had limited knowledge of the purpose of their prescription medications. One woman with low health literacy said, "I take high blood pressure and that purple pill I take in the morning; heartburn I guess." The interviewer then asked, "Do you take any other medications?" She replied, "Yeah, but I don't know what they are." Despite limited knowledge of the purpose of specific medications, vulnerable interviewees often reduced self-management responsibilities to compliance with prescribed medications. When asked what they could do to improve their health or what advice they might give others in their situation, "take your medications" was the most frequent and often the only response they gave. The nonvulnerable sample saw medications as part of a larger plan to maintain health and function.

The perceived importance of office visits and prescription medication was clearly evident, but there was little mention of the role of medical care in health maintenance. Few from either sample mentioned receiving any specific advice about mental or physical activity, emotional assistance outside of drug therapy, or nutrition. Physical therapy consults were the most mentioned health-maintenance-oriented resource.

Caring for Family Members

Perceptions of social support and the demands of social networks on the older adult were different in the two groups. For example, the nonvulnerable group watched grandkids only occasionally (a day or two a week) and were not their daily caretakers. By contrast, vulnerable interviewees often provided daily care to grandchildren or great-grandchildren or were a source of shelter to an adult relative who often had a child. When asked "What makes you feel sad or blue?" one woman from the vulnerable sample who takes care of her grandkids replied, "I don't know; I never really thought about it. The kids I guess." This response was quite different from that of a woman in the nonvulnerable sample, who said, "[I] think of something positive, like my grandkids. There is not one thing any of them wouldn't do for me if I called them." Although caring for others was in some cases a clear stressor, there were frequent examples in both samples of interviewees gaining a sense of importance from caring for others. The nonvulnerable group generally did not house relatives in their homes but saw their relatives frequently, and many were very proud of their grandchildren, who were "excellent house guests."

Health Promotion Priorities

The mention of health maintenance behavior was rare in the vulnerable sample but the norm in the nonvulnerable sample. A common response in the nonvulnerable group was to "keep active, keep pushing yourself. Don't just give up and sit down." One man from the nonvulnerable sample, when asked what aging people can do to take care of themselves, said the following:

Activity, mental and physical. My wife once worked for a neurologist and he once told her that highly intellectual people never get Alzheimer's. That's a stupid statement by a physician, to me. I don't think that's true. But I do think you have to stay active. If you don't have physical activity and mental activity, you're going down hill and quickly.

When asked what recommendations they would give to others who were aging, those from the vulnerable sample consistently said to "see your doctor and take your medications." One man whose wife had had a stroke and whose mother had lost a leg to diabetes stated, "I only have hypertension, high cholesterol, and diabetes. I think that's the worst right there [diabetes]. Watch what you eat, don't overexceed alcohol, because that's a lot of sugar."

Whereas vulnerable sample interviewees verbalized an awareness of the need to watch what they ate and to try to eat vegetables, this group generally did not restrict food for health maintenance: "My son brings me candy bars. And of course chips. I love chips. I love onions, and they're good for the heart, too." This comment contrasted with the statement of a nonvulnerable interviewee: "I try to eat healthy. I eat poultry and green vegetables. I love green vegetables. I don't eat all that much. I like fruit. I have fruit everyday."

With regard to physical activity, there was a consistent report of range-of-motion exercises to avoid stiffness among the vulnerable interviewees. In fact, the report was remarkable in its consistency from interview to interview within this sample. A typical response was "I worked up to 75 slides every night. I do 'em, cause if I don't I know I'm gonna be stiff." (*Slides* seemed to refer to a knee bend from a lying down position.) Among the nonvulnerable interviewees, there were more reports of physical activity, such as walking, for purposes other than stiffness treatment. The philosophy about activity level and aging was quite different between the vulnerable and nonvulnerable groups. The nonvulnerable group consistently reported that

above all else older adults need to stay active. As one interviewee commented, "I wanna work, it keeps me motivated. It keeps me moving. I do a lot of walking. I walk a lot at work, and then I come home and if the weather is nice I walk a lot out." By contrast, there were few reports of regular physical activity, other than "slides" from the vulnerable sample.

Expectations About Health and Aging

Expectations about health and aging differed between the two groups. The low health literacy group generally believed they were old and not going to live much longer, and, as a result, they reported few if any life goals. When asked if there was anything she would like to see changed or different in her life, one low health literacy woman responded, "Not really, I'm too old to worry about that. I'm 72, I ain't gonna live that much longer." The nonvulnerable group tended to feel that they had much yet to live for and could have a good life if they took care of themselves. A 69-year-old woman with good health literacy reported, when asked what she thought was the key to her health, "My attitude; my willing to want to live a long time. My willingness to want to see my grandchildren grow up."

The low health literacy group had priorities of being comfortable, getting rest, and eliminating pain. The nonvulnerable group was more likely to report life goals such as those of the woman quoted above. Goals included seeing milestones of children, grandchildren, and great-grandchildren; taking care of the home; working; and socializing. Generally, those in the vulnerable group had difficulty expressing goals, but they most frequently mentioned resting, visiting with or caring for family, viewing television, and attending church. Interviewees who had lived most or all of their lives within poorer Midwestern communities (rural or urban) had low awareness and low expectations regarding healthy aging. In contrast, individuals in the vulnerable group who had had earlier life experiences that had exposed them to alternative social contexts had higher expectations regarding aging and health. For example, one man with low health literacy had lived in the same house and low-income neighborhood in which he had been born and raised. He had been away during the middle years of his life traveling and singing with a doo-wop band and had lost 60 lbs a few years earlier, recognizing the health risks of being obese. This individual was well aware of the importance of walking, limiting calories, and watching his weight to avoid making his diabetes worse.

DISCUSSION

We analyzed in-depth, home-based interviews comparing two samples of urban-living older adults: one with moderate to good health literacy and the other with low income and low health literacy. We found important differences between these groups in health promotion priorities and expectations for health and successful aging. In addition to personal resources frequently noted in the literature such as self-monitoring and self-regulation, we identified the following as important: (a) perceiving providers and medications as just one self-management tool, (b) caring for and supporting family members, (c) having physical and social activity as a priority, and (d) holding expectations for health and successful aging. The capacity to know when and where to look for information

and how to interpret it seemed a particularly key skill for both illness treatment and health maintenance. Individuals with this skill seemed more knowledgeable about their illness and health and more proactive and less anxious about the illness. Information access was more limited in the vulnerable sample, as one might expect.

Models of effective longitudinal care for chronic conditions all recommend that primary care practices provide self-management education and support. One of the critical steps to effective self-management support is getting to know the patient and his or her priorities and expectations (Bodenheimer, 2007). If an older adult has low expectations for health, then education and resources for self-management without discussion of expectations and priorities may have little impact. Having low expectations and few health-related priorities may be particularly problematic for self-management among socioeconomically vulnerable older adults, because the stories relayed by our participants suggest that these perceptions develop over a lifetime of experiences. One observation from our interview data is that stories of life experiences with illness, accidents, and death were more common among the vulnerable interviewees, and examples of disability-free aging among this group were few. The nonvulnerable sample had more stories of healthy aging and of persons managing the impact of their illnesses. We can not say from our data whether this was due to actual differences in experience, differences in perspective, or both. Regardless, there were differences in perceptions, and these may translate to expectations and priorities. Expectations and priorities are likely to have significant implications for chronic illness care and health disparities research. As noted earlier, Sarkisian and colleagues (2005) have developed a survey measure of expectations that taps the extent to which people feel that aging is accompanied by undesirable and inevitable social, psychological, and physical consequences. So far, this measure has been associated with physical activity, and we suspect that it will be associated with other self-management behaviors as well.

In our samples of interviewees, there was a clear tendency for the nonvulnerable group to be more engaged in mental and physical activity and for that activity to be considered a key to successful aging and life meaning. These health-maintenance-oriented older adults appeared to gain meaning from being physically and mentally active. If one considers activity engagement to be a key ingredient to life meaning, then health maintenance may become a priority role. Vulnerable interviewees were less engaged in life activities outside of their immediate life space and were more likely to have roles that involved caring for others in their home on a daily basis. In fact, the amount of care that the older vulnerable interviewees were providing was in cases very substantial. In many cases this was a source of significant stress, but there were cases where it gave a sense of mattering and interdependence with others. In any case, the roles of vulnerable older adults seemed to be viewed as sustainable by maintaining comfort, freedom from pain, and rest.

This single qualitative study has clear limitations. We sampled from two distinct clinic populations from one city. Our data collection was exploratory in nature and not intended to provide tests of causation. However, as hypothesized, we discovered differences in aging expectations and self-management priorities between vulnerable and nonvulnerable older adults. If further

research confirms such differences by educational attainment, socioeconomic status, and/or health literacy, this may be an important target for health disparities research. If priorities flow in large part from social roles that provide one a sense of importance and mattering, it is important to better understand these social roles and sources of identity. Social cognitive theory interventions attempt to improve priority for a target behavior in part by building positive expectations for the outcomes of that behavior. Tailoring messages so the outcomes for which outcome expectations are to be built fall within an individual's life priorities may be particularly important for self-management programs in vulnerable populations. Tailoring has achieved efficiency in application to large populations through the use of Internet data collection and algorithms. How to scale tailored messages for a population that has limited information access in general and Internet access in particular is a significant challenge. Whether carefully designed social marketing campaigns with messages targeted to socioeconomically vulnerable older adults could be effective in this regard is not known.

Getting to know a population is critical to the success of any social marketing effort. Evaluating and applying existing measures of self-management self-efficacy (e.g., Patient Activation Measure), resources (e.g., Chronic Illness Resources Survey), and expectations (e.g., expectations regarding aging), and new measures of self-management knowledge and awareness, life priorities, and social network demands from and support to samples of vulnerable older adults, could prove valuable in improving researchers' knowledge of factors that influence self-management in this population. With this improved knowledge, experts could develop an efficient tool that measures important elements for guiding self-management support. Applied to individuals, such a tool could screen and flag patients who have low self-management capacity and could help "jump-start" providers in getting to know the patient in ways very relevant to self-management support. Such a tool would have to go through multiple cycles of testing and revision to achieve brevity and validity, and even then significant effort would be needed to implement such a tool. However, without significant effort and progress in knowledge of self-management, chronic illness care will fall well short of desired outcomes, particularly among vulnerable populations.

CORRESPONDENCE

Address correspondence to: Daniel O. Clark, PhD, Indiana University Center for Aging Research, Regenstrief Institute, Inc., Indiana University School of Medicine, 410 West 10th Street, HITS Building Suite 2000, Indianapolis, IN 46202-3012. E-mail: dclark@regenstrief.org

REFERENCES

Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood Cliffs, NJ: Prentice Hall.

Baranowski, T., Perry, C. L., & Parcel, G. S. (2002). How individuals, environments, and health behavior interact: Social cognitive theory. In K. Glanz, F. M. Lewis, & B. K. Rimer (Eds.), *Health behavior and health education: Theory, research, and practice* (2nd ed., pp. 165–184). San Francisco: Jossey-Bass.

Bass, P. F., III, Wilson, J. F., & Griffith, C. H. (2003). A shortened instrument for literacy screening. *Journal of General Internal Medicine, 12*, 1036–1038.

Bellg, A. J. (2003). Maintenance of health behavior change in preventive cardiology: Internalization and self-regulation of new behaviors. *Behavior Modification, 27*, 103–131.

Bodenheimer, T. (2007). A 63-year-old man with multiple cardiovascular risk factors and poor adherence to treatment plans. *Journal of the American Medical Association, 298*, 2048–2055.

Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. (2002). Patient self-management of chronic disease in primary care. *Journal of the American Medical Association, 288*, 2469–2475.

Callahan, C. M. (2001). Quality improvement research on late life depression in primary care. *Medical Care, 39*, 772–784.

Centers for Disease Control and Prevention. (2007). *State of aging and health in America report*. Washington, DC: U.S. Department of Health and Human Services.

Chodosh, J., Morton, S. C., Mojica, W., Maglione, M., Suttorp, M. J., Hilton, L., et al. (2005). Meta-analysis: Chronic disease self-management programs for older adults. *Annals of Internal Medicine, 143*, 427–438.

Clark, D. O., Stump, T. E., Miller, D. K., & Long, J. S. (2007). Educational disparities in the prevalence and consequence of physical vulnerability. *Journal of Gerontology: Social Sciences, 62B*, S193–S197.

Clark, N. M. (2003). Management of chronic disease by patients. *Annual Review of Public Health, 24*, 289–313.

Clark, N. M., Gong, M., & Kaciroti, N. (2001). A model of self-regulation for control of chronic disease. *Health Education and Behavior, 28*, 769–782.

Corbin, J., & Strauss, A. (Eds.). (1988). *Unending work and care: Managing chronic illness at home*. San Francisco: Jossey-Bass.

Counsell, S. R., Callahan, C. M., Buttar, A. B., Clark, D. O., & Frank, K. I. (2006). Geriatric Resources for Assessment and Care of Elders (GRACE): A new model of primary care for low-income seniors. *Journal of the American Geriatrics Society, 54*, 1136–1141.

Dean, K. (1986). Self-care behavior: Implications for aging. In K. Dean, T. Hickey, & B. Holstein (Eds.), *Self-care and health in old age* (pp. 58–83). London: Croom Helm.

Glasgow, R. E., Strycker, L. A., Toober, D. J., & Eakin, E. (2000). A social-ecologic approach to assessing support for disease self-management: The Chronic Illness Resources Survey. *Journal of Behavioral Medicine, 23*, 559–583.

Hibbard, J. H., Stockard, J., Mahoney, E. R., & Tusler, M. (2004). Development of the Patient Activation Measure (PAM): Conceptualizing and measuring activation in patients and consumers. *Health Services Research, 39*, 1005–1026.

House, J. S., Lantz, P. M., & Herd, P. (2005). Continuity and change in the social stratification of aging and health over the life course: Evidence from a nationally representative longitudinal study from 1986 to 2001/2002 (Americans Changing Lives Study). *Journals of Gerontology: Psychological Sciences and Social Sciences, 60B*(Special Issue II), 15–26.

Institute of Medicine. (2003). *Priority areas for national action: Transforming health care quality* (K. Adams & J. M. Corrigan, Eds.). Washington, DC: National Academies Press.

Lorig, K. R., Ritter, P. L., Stewart, A. L., Sobel, D. S., Brown, B. W., Bandura, A., et al. (2001). Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Medical Care, 39*, 1217–1223.

Morgan, D. L. (Ed.). (1993). *Successful focus groups*. Newbury Park, CA: Sage.

Morrow, D., Clark, D., Tu, W., Wu, J., Weiner, M., Steinley, D., et al. (2006). Correlates of health literacy in patients with chronic heart failure. *The Gerontologist, 46*, 669–676.

Ory, M. G., & DeFriese, G. H. (Eds.). (1998). *Self care in later life: Research, program and policy perspectives.* New York: Springer.

Pearlin, L. I. (1999). The stress process revisited: Reflections on concepts and their interrelationship. In C. S. Aneshensel & J. C. Phelan (Eds.), *Handbook of the sociology of mental health* (pp. 395–416). New York: Kluwer Academic/Plenum.

Rosenberg, M., & McCullough, B. C. (1981). Mattering: Inferred significance and mental health among adolescents. *Research in Community and Mental Health, 2,* 163–182.

Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist, 55,* 68–78.

Sarkisian, C. A., Prohaska, T. R., Wong, M. D., Hirsch, S., & Mangione, C. M. (2005). The relationship between expectations for aging and physical activity among older adults. *Journal of General Internal Medicine, 20,* 911–915.

Schulz, R., & Heckhausen, J. (1996). A life span model of successful aging. *American Psychologist, 51,* 702–714.

Seidman, I. (1998). *Interviewing as qualitative research.* New York: Teachers College Press.

Stryker, S. (1968). Identity theory and role performance. *Journal of Marriage and Family, 30,* 558–564.

Taylor, J., & Turner, R. J. (2001). A longitudinal study of the role of significance of mattering to others for depressive symptoms. *Journal of Health and Social Behavior, 42,* 310–325.

Appendix

Script for In-Home Interviews

We are interested in learning more about what older adults like you do to keep yourself healthy or take care of yourself. I am going to ask you a series of questions about your health and your health problems and the day-to-day things that you do to avoid getting sick or injured or disabled. Even for those health problems that you have had for a long time, we are interested in how you manage them. First though, I want to get to know you a little...

MAIN QUERY ONE: Get to know the person.

Who lives here with you?
Who are your family members?
How many children do you have? Do they visit and how often? Live close by?
Talk about pictures on walls.
Do you take care of any one?
How long have you lived in Indy?
How has neighborhood changed over the years?

MAIN QUERY TWO: What are their health conditions, and how does their health affect their ability to do the things they enjoy and to carry out their responsibilities.

As I ask these questions, keep in mind that there is no right, or wrong answer...

TIME: 15 minutes

1. What long-time health problems do you have? (Record list of health problems, if more than three ask patient to identify the three that give him or her the most problems.)

2. Which health condition gives you the most trouble? (**Get specific with these probes** Symptoms, function impact, mood impact, costs, burden of care). Why? How?

   2a. Is there another health condition that gives you a lot of trouble?

3. Who helps you with this/these health problem(s) [problem/condition, #1]? How or what do they do?

MAIN QUERY THREE: What activities are enjoyable to them and what is important in their lives...

4. What activities do you do on a day-to-day basis? (Weekly, monthly, yearly ... work, shop, clean, watch TV, take care of grandkids, visit people, who comes over?)
   Tell us about a typical day for you – start to finish

5. Which activities are most important to you? Why?

6. Are there other activities or hobbies that you do for enjoyment? (Any hobbies, entertainment, social activities, conversation—think have to probe on this one)

7. Do you take care of anyone? Does anyone count on you to do anything? If so, what?

8. What do you do to stay healthy? What do you eat? Exercise? Medications? Some people find it hard to take their meds everyday. Do you have times when it is difficult? How do you relieve stress?

Now, coming back to what you do to maintain your health...

TIME: 10 minutes

9. Does ___ [health problem, #1or #2] make it hard for you to do the activities that you **WANT** to do? (For self or others)

10. Does ___ [health problem, #1or #2] make it hard for you to do the activities that you **NEED** to do? (For self or others)

11. Does feeling down ever make it hard to do things for yourself or others?

   (If YES ...)
       11a. Do you often feel sad? (if yes)
       10a1. Do you feel sad almost every day?
       11b. Would you say you are depressed?

MAIN QUERY FOUR: What do they do AND not do to self-manage their significant health conditions, what helps or hinders this self-management.

TIME: 20–30 minutes

Please think of your most important health conditions (Interviewer: list these, #2).

12. What do you do to take care of these health conditions? (Interviewer **probe a lot here**; what do you do on a daily basis? What do you do when it gets bad? Do other people do things to care for you and your condition?)

Interview: REPEAT 12-13 questions for each management task

13. Are there things that you do to make it easier to ... (list task, #10)? What? How?
   (Does your clinic do anything to make it easier to do this task? Is there something they could do to make it easier to do this task?)

14. Are there things that make it hard or get in the way of doing . . . (list task, #10)? What? How?
    (Is there something your clinic could do to get rid of these things that make it harder? Is there something your family could do to get rid of these things that make it harder? Is there anyone else that could get rid of these things that make it hard to do this task?)
15. Have you heard of anything that other people do for (list conditions, #1). (Probe—maybe from television, news, magazines, family)
16. Has your doctor or nurse given you any ideas of things to do to take care of your (list conditions, #1)?
17. Did you try these ideas? What did you find when you tried them? (interviewer—this question refers to responses from 13 and 14).
18. If someone you cared about had [problem/condition, #1], what sort of advice would you give them to help them manage the problem? What would you tell them NOT to do?
19. We are looking for ways to improve current programs or expand services in our current health care system to help people better care for themselves and their conditions. Could you be as upfront as possible and tell us what you would want to tell your doctor or the people that run Wishard Hospital about what you need to help you manage . . . (list condition, #1).

Probe: Is there any information they could give you? Is it hard to get information? Is the information clear?

Is there something you need that is hard to get? Maybe medicines, a cane, things to help you in your home like a handrail?

When you have questions, do you know where to go to ask and are you able to get answers?