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“Is it Half Full or Half Empty?” Affective Responses to Chronic Illness

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Abstract

Using a combined qualitative/quantitative approach, we interviewed 132 older African–Americans and whites with either osteoarthritis of the hip or knee (OAK/OAH) or ischemic heart disease (IHD) to address two questions: 1) What types of reactions to illness are expressed by this group of older adults who have OA or IHD? 2) Are there differences in the characteristics of the respondents who respond more positively than those who respond more negatively? The responses were coded to illustrate those that reflected positive, negative, or combined (positive/negative) statements. The majority of the respondents, who were categorized as positive or combined, approached the illness experience with statements illustrating their ability to cope with their illness and adapt their lifestyles to the limitations imposed by the disease such as acceptance, feeling that others were worse off, or changing their lifestyles to adapt to their limitations. Those expressing negative reactions to their illness were fewer in number and responded with terms reflecting loss of identity, physical limitations, and other disease symptoms. The differences were more pronounced between the positive and negative groups where the latter were somewhat more likely to be African–American and female and significantly more likely to have less income, greater perceived disease severity, and more disability. We should look to the larger group in both the positive only and combined responses to explore how culture may play a role in perceptions of subjective well-being and the importance of “the local worlds of experience” experienced by both men and women, and African–Americans and whites. This study illustrates that using a simple, open-ended question that stimulates older people to narrate their reactions to having a chronic illness may allow clinicians to identify the persons most at-risk and intervene appropriately.

Keywords

African-Americans; Chronic illness; Heart disease; Osteoarthritis; Qualitative/Quantitative research

Introduction

As the U.S. population has aged and incidence of chronic illness has increased, an awareness of what having a chronic illness means to patients has also grown. Researchers have begun to study how illness affects daily experience and how older people redefine or maintain their identity in the face of illness (Atchley 1989; Becker 1993; Becker and Newsom 2005; Clark *et al.* 1991; Conrad 1987; Kleinman 1988; Merck Institute of Health and Aging 2004). However, the extent to which an individual's feelings about having a life-threatening or debilitating chronic illness may reveal the potential for important adaptive strategies is less well understood. Recognizing how elders feel about the changes in their lives stemming from illness may help providers assess their adaptive strategies and design appropriate interventions to sustain independent living.

In this paper, we draw on research involving in-depth qualitative inquiry to understand how older adults adapt to living with a chronic illness (Becker 1993; Becker and Kaufman 1995; Becker and Newsom 2005; Charmaz 1983, 1987, 1991; Corbin and Strauss 1987; Kaufman 1986, 1988a, b; Kleinman 1988). Prior research has shown that chronic illnesses affect body, self, and biographical time. When illnesses are first diagnosed, people may feel that their bodies have failed them, leading to concerns about their ability to continue the activities that were meaningful to them in the past. Successful accommodation to illness requires appropriate illness management but it also necessitates "actions that give their life continuity and meaning despite the changes" (Corbin and Strauss 1987, p. 251).

Recently, researchers have suggested that after diagnosis, patients may move from previously held negative self-images to more positive ones (Dinos *et al.* 2005). In general, when older adults experience a chronic and sometimes debilitating illness, they do tend to rebuild self-identity (Atchley 1989; Becker and Newsom 2005; Charmaz 1991; Corbin and Strauss 1987). This may be a key element in successful adaptation. Healthcare practitioners need to understand the factors that promote or impede this process.

Age does not appear to be a limiting factor in the re-establishment of patients' self-images. In fact, Becker (1993) and others emphasize that continuity of self-identity is a driving force for older adults as they face changes due to illness (Kaufman 1986), relocation (Myerhoff 1979; Rubenstein 1988), retirement (Skirboll and Silverman 1992) or other disruptive influences. Qualitative research is especially useful in elucidating efforts to maintain such continuity, as it captures "the unique ways in which people interpret how their illnesses affect their responses to symptoms, treatment, and the modifications of daily life that they may make to accommodate the illness" (Becker and Kaufman 1995, p. 167). An example might be two similarly aged women who experienced stroke and who demonstrated differences in adapting to the demands of rehabilitation (Becker and Kaufman 1995). One woman was extremely diligent and persistent in carrying out treatment recommendations prescribed by the physical therapist, while the other was resistant and "non-compliant" to similar treatment recommendations. While one had been an extremely compliant and persistent person throughout her life, the second required greater personal control over care. Successful treatment strategies in these cases could be developed only through recognition of their different personal philosophies of illness management.

Such studies are particularly relevant because of the prevalence of negative attitudes about illness in old age and misperceptions about the abilities of older adults to positively adapt to their illnesses (Sankar 1986; Young and Kahana 1989). This dimension of ageism may contribute to a lack of realistic interventions to support continued independent functioning.

It is well known that culture plays a critical role in how individuals perceive health and illness and the choice of the practices they use to treat their illnesses (Becker 2003; Becker and

Newsom 2005; Chrisman and Kleinman 1983; Ware and Kleinman 1992; Zborowski 1952; Zola 1973). However, the ways in which older persons react to their chronic illness are not well understood and may differ across ethnic, racial, cultural, or gender groups. Ware and Kleinman (1992) state that, "Health and suffering, like other existential states, are patterned by culture and *realized* as local worlds of experience"(p. 547). An individual's interpretation of illness experience is affected by those "local worlds of experience" that may lead to very different responses and offer different resources for coping than those of another with a similar illness. The work of Becker (2003) and Becker and Newsom (2005) highlight how differences in cultural values and the experience of racism among older ethnic minorities can provide a context for understanding the development of a philosophy about illness and strategies for its management.

This paper focuses on the illness experiences of 132 African-Americans and whites who met research criteria for osteoarthritis of the hip or knee (OAK, OAH) or ischemic heart disease (IHD). It attempts to address some of the unanswered questions about what influences the illness experience and how it is expressed. This group participated in a four-year National Institute on Aging study of the self-management of chronic illness. Arthritis and heart disease were chosen as the index illnesses for this study because of their prevalence in the elderly population and their importance as causes of death and disability, and because they may stimulate different reactions to illness management. These illnesses differ in symptoms, seriousness, and associated disability (Nolan *et al.* 2004).

Using a combined quantitative and qualitative approach, the paper addresses the following questions: 1) What types of reactions are expressed by this group of older adults who have OA or IHD, and, 2) are there differences in the characteristics of the respondents who respond more positively than those who respond negatively?

Methods

Sample

The 132 respondents in this study were a sub-sample of participants drawn from a larger study ("The Process of Self-Care Management for Older African Americans and Whites"). These elders from Allegheny County, Pennsylvania, were followed over the period 2001–2004. At baseline, all met research criteria for either IHD or OA and had no obvious indication of cognitive impairment.

The sample for the larger study, with an over-sample of African Americans for comparative purposes, was randomly drawn from individuals aged 65 or older who were listed in the Medicare enrollment file for Allegheny County as of April 2001. Community dwelling adults aged 65 and over who resided in Allegheny County during the recruitment period, who met screening criteria for one of the two index diseases, and who had no obvious indication of cognitive impairment were eligible to participate in the study. Screening for the two index diseases was indirect, based on a series of self-report questions asked in the recruitment interview.

Eligibility for OA was based on a series of self-report questions derived from the National Health and Nutrition Examination Surveys (NHANES, Dillon *et al* 2006). Respondents had to report that they had (a) pain in their hip or knee on most days for at least a month, (b) pain when walking or standing for at least half the days during the preceding month, and (c) pain of this severity for a period of at least 6 months. In order to be eligible for IHD, respondents had to report one or more of the following; a doctor told them that they had or previously had a heart attack or myocardial infarction (MI) (in the last 5 years), congestive heart failure, angina, or a valve problem, rheumatic heart or hypertensive heart disease; or that they had ever had

coronary bypass surgery, angioplasty of the coronary arteries, or other heart surgery. Approximately 50% of those who were interviewed and found to be eligible joined the study. A total of 1,128 enrolled, of which 551 met the criteria for OA; the remainder met criteria for IHD. Among those found to be eligible, African-Americans, younger people (age 65–74), those with more education, and those with more health conditions were more likely to participate.

Procedures

Participants were interviewed four times over a 30-month period, with the first three interviews conducted in-person and the fourth by telephone for the majority of participants. However, at Time 4, 155 of the respondents (drawn from the remaining 927 in the study) were interviewed in person (either in their homes or in a mutually agreed-upon place) and received, in addition to a structured interview protocol, a qualitative in-depth interview that examined both their daily routines for treatment of their illness and their feelings about having the illness. The total interview averaged approximately 2 h. The duration of responses to the final question regarding “feelings about having OA or IHD” ranged from a few minutes to as much as 5–10 min, with some respondents providing only a few comments or none at all. The entire interview was audio taped and transcribed verbatim. Participants were purposively selected for this qualitative interview to reflect differences in illness, race, and gender, with the intention of equally representing these characteristics. In addition, a small number of study participants who were identified as having difficulty in completing a telephone interview (due to hearing deficits or other health related problems) were included in the 155 selected for the in- person interview.

The focus of this paper is the question, “What are your feelings about having your illness?” To explore older adults’ emic perceptions about their illness, we asked them to describe their feelings about having OA or IHD. The open-ended query allowed the elders to frame their feelings in whatever manner they saw appropriate because interviewers did not prompt responses. Because not everyone responded to this question (because of limited interview time, interviewer judgment, not addressing the question, or refusals), responses were available for only 132 of the 155 respondents.

The in-home interview was conducted by research assistants (both African-American and white) who had, for the most part, participated in the project during all 4 years. The long-term interviewer-subject relationship established with participants fostered a rapport that enhanced the candidness of responses and quality of the data collected. Respondents received \$25 for each interview. All participants were assured confidentiality, following the guidelines of the University of Pittsburgh’s Institutional Review Board, which approved the study.

Measures

Quantitative measures

For examining responses to the “feelings” question, independent variables included socio-demographic indicators, social support measures, and health status.

Socio-demographic measures included age, gender, race (African-American or white), education, and income. Education was dichotomized into two categories: 1) some college or more, and 2) a high school degree or less. Income was dichotomized as 1) \$20,000 annual income or more or 2) less than \$20,000. The adequacy of the respondents’ finances was analyzed as 1) somewhat or very inadequate versus 2) adequate or more than adequate. Social support measures included marital status and living arrangement. Health status measures included index disease (IHD or OA) and other general health status measures. Disease-specific measures included duration and self-reported severity.

Because the standardized scales we utilized to assess disease severity were not sufficiently comparable between illnesses, we relied on the respondent answers to the question “Please think about how your arthritis (or heart disease) and all of its symptoms have been during the past month. Would you say it’s been very severe, severe, moderate, mild or no symptoms at all?” to measure disease severity. Based on their responses to this question, the respondents were clustered into two categories: moderate to very severe (high severity) or mild or no symptoms (low severity) (Table 1).

More general health status measures included the total number of chronic conditions reported by the respondents (from a list of 19 conditions) and self-reported disability (count of six activities of daily living tasks [ADL] and six instrumental activities of daily living tasks [IADL]). We also used the SF-12 (version 2), to measure self-reported health. The SF-12 v2 is a multidimensional generic index of self-reported health status with items that assess eight dimensions of health, and includes two summary scores, one for physical health and one for mental health (Ware *et al.* 1996). It has been extensively validated and tested for reliability and has been normed to the U.S. population. We used the two SF-12 v2 summary scales in the analysis: the physical component summary scale (PCS), and the mental component summary score (MCS), both of which range from 0 to 100, with higher values indicating better health. We assessed depression using the 10-item Center for Epidemiological Studies Scale (CES-D) (Andresen *et al.* 1994).

Qualitative responses

The process of coding and theme development followed rules established by Strauss and Corbin (1990), Schoenberg *et al.* (2003) and others. Using an iterative approach, the two lead authors each read and reread the responses of all 132 cases. After eliminating one-word replies or answers so brief that interpretation would not be possible, the coders classified all responses into clusters reflecting similarity in the meaning of words or phrases, such as “I feel fine” or “It doesn’t bother me,” into a category they labeled as positive. A negative cluster included such responses as “I am limited in what I can do” or “I feel depressed.” These were further subdivided by substantive area. Where responses included a combination of both positive and negative terms, they were assigned to the combined category. In a small number of cases ($n=8$), respondents replied with phrases that were neither positive nor negative and did not address the question. These cases were not used in analyses.

For cases that were difficult to classify, coders developed rules for classification that were used throughout the coding process. The coders met regularly to discuss these cases and come to a consensus. Because of the similarity in responses for both OAK/OAH and IHD, an overlapping coding scheme was developed for both illnesses. Table 2 and the Appendix describe themes and illustrative responses from participants.

Analyses

As part of the following discussion, we provide individual case material in the language of participants to illustrate variations in feelings about having a chronic illness (OA or hip or knee or IHD). As described earlier, these were classified broadly into positive and negative clusters and then subdivided into themes within categories. We also examined bivariate relationships between the coded responses and socio-demographic, social support, and health measures. Finally, we fit a multinomial logistic regression model to examine the degree to which the identified themes could be accounted for by each independent variable.

The mixed method approach has the advantage of “maximizing the strengths and minimizing the weaknesses of each” (Knafl *et al.* 1988, p. 30). Despite the challenges of combining

qualitative and quantitative data (Groger and Straker 2002), the combination allows the reader to “grasp the rich complexity of the context” (Miller and Crabtree 1994, p. 344).

Results

Table 2 shows the themes and their categorization into positive, negative, and combined categories. The table also shows the relative frequency of use of these themes by category. Eighty of the 132 respondents made only statements that were categorized as positive, while 18 respondents made only statements categorized as negative, and 34 made statements of both types. The themes labeled “acceptance of the disease,” “no effect,” or “no problem” were the most frequently made positive statements. Among the themes categorized as negative, the most frequently mentioned were “limitations” and “restrictions” imposed by the diseases. Frequencies for each subtype are shown in Table 2.

The most common characteristic of the positive or combined group was their affirmation that the illness (OA or IHD) had little effect on their lives and was generally accepted as a part of life. Consider, for example, Mrs. T., a 73-year-old white woman who has had arthritis of the hip for many years. Despite her poor self-rated health and high disease severity, she described her feelings about having OAH as follows:

Why not me? I never think ‘why me’... It’s part of growing old; it’s part of heredity, I guess. Its part of life and you’re just afflicted with it. Some people never get any of these and some do, and I’m one of the ones that do, so I just feel, why not me? That’s the way it is. I’ve accepted it. (*Themes: acceptance, fatalistic*)

Mrs. T. went on to say:

Life is tough. What do they say? Life is what happens to you when you have other plans. I have other good things: I still have my own teeth. I don’t have any false things. I’m still able to walk around. I’m still able to drive. I still have my house. I still have my car and everything. I feel lucky in a lot of ways. My family loves me. (*Themes: positive attitude, no effect/no problem, positive lifestyle changes*)

Similarly Mrs. S., a respondent with severe IHD, reported feelings of acceptance and adjustment to the limitations of the illness. She is an 87-year-old white woman who lives alone, does her own housework and gardening, makes Belgian lace, plays the piano and accordion, and goes dancing every Monday night. Commenting on her heart condition, she reported that her illness is not creating problems and is having no effect on her life. She responded positively to the question about her feelings: “I was really surprised! I could say, ‘oh my, I had all that done, you know, big heart attack. Or you can say, ‘okay, it’s over, let’s get a life.’ You know, what do you want to do? It depends on how you look at it, what your attitude is. Is it half full or is it half empty?” (*Themes: positive attitude, acceptance*).

Some respondents, regardless of illness type, reported they were cured or fixed after they had experienced either surgical procedures for their heart disease or surgical replacement of hip or knee. For example, an OA respondent reported, “(I’m) glad it’s gone.” Another reported, “(I’m) glad I don’t have discomfort anymore.” A respondent with IHD reported, “I don’t think about it... I think it’s cured. To me its over, the heart is better.” (*Theme: feeling cured*)

For other respondents there was also a sense of relief that, “at least it isn’t cancer” or that others were worse off than they were. For example, one said, “Life is good if you look around,” or “I feel that a million people are worse off than me” (IHD). Still another reported, “A heart condition is nothing like cancer.” A respondent with OA said, “I’m sure it will never kill me, (but) if I had cancer...” (*Themes: better than other diseases or other people worse off*).

Some respondents turned to religion, prayer, or spirituality to deal positively with their illness. For example, one reported, “I just trust in the Lord and I know He’s able to heal me in his own time... I feel myself blessed” (OA). Another said “If God wants it to be this way, (I’m) in God’s hands,” or “I have a lot of faith.” Still another said, “(I) believe that the higher power keeps me in perfect peace.” “(I) don’t worry about it because I prayed about it” (IHD). (Theme: religion/spirituality)

There were also those who turned to fatalism to characterize their acceptance of their illness and reported “(You) can’t fight it, it’s inevitable... have to die of something.” “Whatever is going to be, is gonna be.” “These things are meant to be” (IHD). (Theme: fatalism).

There were, however, some differences in how those with OA or IHD responded to the question about “Feelings about their illness.” While some of their responses are associated with the nature of the illness (IHD is generally asymptomatic whereas OA sufferers express considerable pain and daily physical discomfort), there were other differences. Those with heart disease often answered with feelings of surprise and sometimes alarm at the seriousness of the illness or concerns about how it would affect their family. For example:

- An 80-year-old white female reported, “I don’t like it... When that word came up it took me a long time to accept it because at some point in time I said to the cardiologist... explain to me this word heart disease... I was never told I had heart disease and that’s hard for me to accept. I thought I had a micro-valve problem and so I guess I do have heart disease, but it’s not poison ivy. I know where I get poison ivy.”
- A 67-year-old white woman said, “I’m very upset over it. And I’m worried. And I always think, gee I’m gonna be 70 now. How much longer am I gonna live with that heart stuff... I’m worried about it and I don’t want it.”

Thirty-four respondents reported both positive and negative feelings about their illnesses. Those respondents in the “combined” category sometimes started out narrating the negative aspects (such as loss of strength, loss of former identity) but at some point realized that they were able to deal with them in constructive ways.

An example is Mr. L., a 76-year-old African–American man with IHD, who talked about his feelings after having a heart attack and his approach to life afterward.

Well, I can tell it restricts mostly everything you do; you know, it changes your lifestyle. It changes because you can’t do a lot of heavy exercising or heavy work... Oh, it makes you feel just, you know, like weak. I mean, I know I’m not strong. Low self-esteem, you could call it, and then you realize that there are lots of things you can still do, you know, and you don’t give up ... when you were younger and you were stronger I had to do less things and don’t do strenuous ... things, you, know, be careful, and ask for help when I need it.... I call my son if there is anything heavy that has to be picked up.

(Themes: restrictions and limitations, negative attitude and positive attitude, and positive lifestyle changes).

There were a number of respondents who narrated how they felt about having their illness only in negative terms, sometimes attributing their illnesses to earlier life experiences or to the limitations imposed on them by their illnesses. For example, a 68-year-old African–American woman who has had osteoarthritis of the hip for many years felt “let down, wondering why it happened to me.”

Is it because I’m not healthy enough? Or what did I do to myself for this to happen to me? It makes me feel sad now because I can’t do the things I used to do. I used to

like to dance, you know. I'm 68 years old and I'm not gonna be out there dancing like Britney Spears or anybody like that, but still I would like to do the swing every now and then. It tires me out; [I] just watch. (*Themes: limitations/restrictions, negative attitude, lifestyle negative changes*).

Both OA and IHD respondents often reported similar complaints about feeling limited or restricted in their activities. For example, they reported, "Slows you down," "Can't do things I want to do" or "Used to do," "Can't walk any distance," "Can't wear heels," "Can't do what has to be done(OA)." Others with IHD reported, "(There are) limitations to what I can do," "(It) makes me feel weak, restricts everything I do," or "(There) am't nothing I can do that I used to do." (Theme: limitations/restrictions, lifestyle negative changes)

The symptom of pain was more common among those with OA and led to complaints such as, "The pain drives me nuts," "Something you can't live with when it starts hurting." Those with IHD were more likely to report negatively about their lifestyle changes, reporting, "Not the person you used to be," "Looked at myself different...had to be more careful about lifestyles," "Changed my way of getting around and doing things."

In the group of eighteen who responded negatively only, regardless of illness type, the respondents expressed feelings of sadness and loss with their illness such as "(I feel) helpless," or "Sometimes I feel sorry for myself," "Makes me feel sad," "Don't measure up"(OA), or "I feel useless," ... "Hard for me to accept," "Makes you feel low"(IHD). (Theme: negative attitude)

The quantitative analysis of the total group provides an overview of the variable responses to living with similar diseases (Table 1). Although only one third (33.6%) of the sample reported having "severe disease", of people reporting positive responses, 20.3% rated their disease as moderate to severe; of those people reporting negative responses, 66.7% rated their disease as moderate to severe. Thus, while disease severity is related to a greater likelihood of a negative response, not everyone with severe disease responded negatively.

Disease severity is not the only factor related to likelihood of positive or negative response. As also shown in Table 1, respondents in the "positive statements only" category had significantly more education and higher socioeconomic status. Respondents reporting positive feelings were less likely to have osteoarthritis and had lower disease severity. They also reported less disability and better quality of life (as shown in the PCS, physical component score). The availability of social supports was higher for those with positive feelings or combined positive/negative responses.

Multivariate analysis

In order to examine the extent to which each demographic and health status measure can account for reported feelings about the disease, we used a multinomial logistic regression model. We compared people who made only negative statements (negative group) or who made both positive and negative statements (combined group) to those who made only positive statements. Results are shown in Table 3.

As shown in the table, participants in the "combined" group were similar to those who made positive statements. Differences were more pronounced between the negative and positive groups. Participants in the negative group were significantly more likely to have incomes under \$20,000, greater perceived disease severity, and more disability.

Discussion

Our goal has been to describe the types of responses that a group of 132 older adults with OAH/OAK or IHD narrated about having their illnesses and the characteristics associated with these respondents. Because these data were collected from a sample of people who had survived 4 years of follow-up, it is not surprising to see a greater proportion expressing positive feelings about living with chronic illness. This preponderance is consistent with a healthy survivor effect. More interesting is what we can learn about those who respond to a chronic illness that they have been living with for some time.

There are limitations to this study. It has somewhat limited generalizability to the larger population of older adults with OA or IHD in the Pittsburgh area because of the purposive nature of the selection process of the 132 participants. However, this procedure facilitated comparisons by disease, race, and gender and the differences identified offer the clinician a clearer understanding of the disease experience through illness narratives of different groups.

Overall, persons reporting positive feelings about their illnesses did so with varied language and content, while those reporting negative feelings about their illnesses limited their responses to symptoms of physical or functional health (i.e., pain, limitations in daily activities, or distress about having the illness). Positive feelings about living with the disease included not only the absence of the effects or symptoms of the illness, but also a variety of adaptive responses, such as “it is one of those things older people get,” or “it doesn’t stop me,” or “I’m not going to let it beat me,” or “the doctors fixed it.” Some looked at others “as worse off” and “preferred their disease to others.” Some participants relied on their strong religious beliefs (“this is something God gave me,” or “It’s God’s will”) and acceptance of the inevitable. By contrast, the negative responses focused on symptoms and a traditional medical model.

We learned that many older adults with chronic illness make the necessary adjustments (through positive attitude, religion, philosophy about life, willingness to modify their routines, etc.) that permit them to continue to live satisfying daily lives in ways similar to their former selves. This occurs even if they define their illness as severe and regardless of type of illness (OA or IHD). On the other hand, a smaller group does not make this transition and see themselves as useless, dependent, or unable to be their former selves. This attitude is of great concern for further decline and dependence.

There may be several reasons for these differences in response. First, the two illnesses and their symptomology differ. While osteoarthritis is generally experienced almost continuously through symptoms of pain or disability, IHD symptoms may be expressed only occasionally and allow for periods of absence of symptoms. IHD allows the individual to resume many former routines and activities. Even though IHD may suggest a more life-threatening illness relative to osteoarthritis, the longer the time from the triggering event, the more likely the respondent is to adapt to having the illness and to seek ways to justify its presence (for example, with statements such as “at least it’s not cancer,” or “I’m cured.”.)

Our results show that people who rated their illness as severe may still respond positively to living with illness. About 20% of our sample fell into this category. Explanations for such adaptive responses range from differences in the socio-demographic and health resources available to differences in “culturally specific philosophies” (Becker and Newsom 2005, p. 221) such as the use of prayer or spirituality to ease the burden of chronic illness. Their study of African-Americans showed that the experience of racism was “instrumental in shaping the responses of African-Americans to their illnesses through cultural values that emphasized independence, spirituality, and survival” (p. 214). Healthcare providers need to understand more about the ways historical experience may shape adaptive responses to illness among different cultural groups.

These findings have important clinical implications. First, we found that a simple open-ended question of the type used here may reveal variations in affective adaptive responses to chronic illness. In addition to the commonly asked questions of self-rated health and other markers of disease severity, clinical providers could profit from eliciting feelings about living with disease that identify positive and negative coping resources. Identification of an at-risk group might then be addressed by interventions tailored to specific needs.

A second clinical implication is that feelings about living with disease vary dramatically, even among people with similar disease severity. Broad indicators of socioeconomic status and social support suggest an independent effect for non-health factors in coping response. This finding suggests that health disparities may also imply disparities in coping resources. Our findings are consistent with research by O'Rand (1996), Farley (1988), Ford (2005) and others, who have shown that cumulative disadvantages over the lifespan affect health and the availability of resources in old age.

Finally, this study used a combination of qualitative and quantitative techniques for data collection and analysis rather than relying on one method alone. By using both research modalities, researchers and clinicians may better address the multiple components that make up assessments of health and illness, which include objective indicators as well as subjective feelings about having an illness.

There are also points of relevance that can be drawn from this combined qualitative/quantitative study that have implications for future research.

- First is the importance of combining research methods to allow for both the emic (person-centered) and etic (a structured, top-down approach) in assessing illness responses. While objective scales provide essential information at the group level, they often omit the variations expressed by individuals with similar diseases, as the previous case illustrations indicate. Researchers have often depended on the predictive characteristics of such scales using measures of self-rated health without recognizing the extent to which they may not reflect the full range of feelings of the research subjects. As noted in the case examples, some respondents addressed their fears about their illnesses, their disabilities, and even pain, but at the same time found sources of pleasure and contentment in a routine of activities or needed assistance from their families.

This finding raises the question of the optimum way to assess how older adults are coping with their chronic illness. Studies such as those by Silverman *et al.* (2000) illustrate the necessity of combining the assessments (emic and etic) in order to provide a fuller and more accurate profile of the subjects' health status.

- Second, some of the most salient characteristics of health and illness can be revealed through personal narratives that illustrate some of the influences that lead to positive or negative reactions to having the illness, such as fear about its seriousness or questions about their own responsibility for the illness. Such attitudes might contribute to or interfere with their ability to cope with the illness. At the same time, some of the features that are most supportive, such as availability of family or social supports, availability of activities that provide distraction, reliance on spirituality to bolster an ability to cope with the symptoms, are more likely to be revealed through the emic approach and perhaps provide essential clues to how to assist those who are less able to cope with their illness. As Harvey and Silverman (2007) indicate, the use of spirituality and prayer may be a useful tool in aiding older adults to cope with their chronic illness.

- Third, this study illustrates the variation in the illness experience. As a group, those with negative statements were somewhat more likely to be African–American, but significantly more likely to have greater disease severity (self-rated) and functional limitations as measured by the IADL scale and their responses to the “feelings” question.

The negativism may be more associated with the painful and debilitating characteristics of OA, which, in this sample, was experienced more by women and African–Americans. We should look to the larger group in both the positive only and combined responses to explore how culture may play a role in perceptions of subjective well-being. This group had the greatest access to resources, including income, education, and family supports. As Becker and Kaufman (1995) noted, there may also be different styles of illness management, reflective of how the respondents managed their younger, healthier lives. Different strategies may be needed to address the disabilities associated with each illness. The importance of “the local worlds of experience” (Ware and Kleinman 1992) may provide some explanation for the positive behaviors experienced by both men and women, African–Americans and whites in this study.

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Table 1
Comparison of Sample Characteristics by Positive, Negative or Combined Statements

	Positive only (N=80)	Combined (N=34)	Negative only (N=18)	Total (N=132)
Demographic/SES				
Mean Age	76.2	77.0	73.9	76.1
% Age 75+	57.0	61.8	44.4	56.5
% Female	46.3	55.9	72.2	52.3
% Black	43.8	55.9	66.7	50.0
% Some college or more education*	46.2	23.5	27.8	37.7
% Income less than \$20,000	39.7	58.8	75.0	49.2
% Finances perceived as inadequate*	25.3	47.1	55.6	35.1
Social support				
% Married	50.6	38.2	38.9	45.8
% Live with others	69.6	55.9	55.6	64.1
Index disease status				
% OA (versus IHD)**	35.4	64.7	66.7	47.3
Mean duration of disease (in years)	11.5	13.8	9.4	11.8
% Moderate or More Disease Severity**	20.3	47.1	66.7	33.6
Other health status measures				
# Chronic Conditions	4.9	4.7	5.4	4.9
# ADL impairments*	1.0	1.8	1.7	1.3
# IADL impairments**	0.8	1.2	1.9	1.1
Mean SF-12 Physical comp scale**	42.5	37.2	34.2	40.0
Mean SF-12 mental comp scale	53.7	52.9	51.5	53.2
% Fair or poor self-rated health*	20.3	20.6	50.0	24.4
Mean CES-D depression scale ⁺	5.3	6.7	7.7	6.0

Chi square test or ANOVA for differences by positive/combined/negative

⁺ $P \leq .10$

* $P \leq .05$

** $P \leq .01$

Table 2
Percent of Individuals Making Statements in Each Theme Category by Type

Theme category	Type of individual statements			Total (N=132)
	Positive only (N=80)	Combined (N=34)	Negative only (N=18)	
Positive category				
Acceptance	42.5	55.9	0	40.2
No effect/no problem	65.0	23.5	0	45.5
Positive attitude	17.5	20.6	0	15.9
Lifestyle positive changes	8.8	8.8	0	7.6
Cured-fixed	6.3	0	0	3.8
Others worse off	10.0	20.6	0	11.4
Prefer to other diseases	3.8	2.9	0	3.0
Religious beliefs	13.8	11.8	0	11.4
Fatalistic	7.5	2.9	0	5.3
Negative category				
Limitations/Restrictions	0	76.5	77.8	30.3
Pain	0	20.6	22.2	8.3
Lifestyle/Negative changes	0	8.8	0	2.3
Negative attitude	0	17.6	55.6	12.1

Table 3
Multinomial Logit Regression Results

	Combined statements vs. positive statements		Negative statements vs. positive statements	
	Odds ratio	95% CI	Odds ratio	95% CI
Demographic/SES				
Black	1.23	(0.45, 3.38)	2.81	(0.56, 14.04)
Female	0.89	(0.33, 2.43)	0.60	(0.13, 2.81)
Some college or more	0.49	(0.16, 1.48)	1.07	(0.18, 6.27)
Income \$20,000 or more	0.59	(0.19, 1.83)	0.13 [*]	(0.02, 0.95)
Index disease status				
Osteoarthritis	1.27	(0.38, 4.28)	0.22	(0.03, 1.84)
Moderate or greater disease severity	2.37	(0.62, 9.13)	27.78 ^{**}	(2.76, 279.1)
Other health status measures				
# of ADL limitations	1.07	(0.71, 1.60)	0.54+	(0.27, 1.08)
# of IADL limitations	1.31	(0.74, 2.31)	3.82 ^{**}	(1.63, 8.94)
SF-12v2 Physical component score	0.97	(0.90, 1.03)	1.05	(0.94, 1.17)
Fair or poor self-reported health	0.29+	(0.07, 1.24)	3.27	(0.43, 24.97)
CES-D depression scale score	1.02	(0.91, 1.15)	1.03	(0.85, 1.26)

+ $P \leq .10$

* $P \leq .05$

** $P \leq .01$

Appendix

Illustrations of themes developed to describe feelings about disease*

Theme category	
No Effect of Disease/No Problem	+ “Doesn’t bother me”, “Don’t think about it”, “I don’t dwell on it”, “Not confining me”, “Not handicapped”, (OA) + “Why worry...can’t do anything about it”, “...don’t let the heart thing bother me”, “Try to ignore it”, “Not having a problem”, “It never stopped me”. (HD)+ “... don’t bother me, you got to keep going. All I want is some relief from this pain. I don’t worry about it no more... you got to live with it”. (OA) + - “I don’t feel bad...as long as you can keep on going and doing... having a little bit of enjoyment. Life is good if you look around... I just can’t do everything I wanna do”. (HD)
Acceptance	+ “One of those things older people get”, “Can’t give into pain, keep going”, “I don’t feel good about it, I just have to accept it”, (OA) + “Learn to deal with it”, “Impossible to forget it and I just live with it”, “I have accepted it, you take the bitter with the sweet”, (HD) + - “I’ve got it, have to make the best of a bad situation...I just can’t do what I used to do.” (OA) + - “It’s there...limitations are part of it.” (HD)
Positive Attitude	+ “Doesn’t stop me, keep going”, “Not going to let it beat me”, “Mind over matter, have to keep going.” (OA) + “...feel good about myself. Look at myself and think I’m great...don’t feel any different”, “Can help ourselves by attitude.” (HD) + - “Try to feel sorry for myself...see a lot of people younger than me walking on crutches. It hurts me to be like this... I’m so used to taking care of me. When you start giving up and letting go, you are in trouble. As long as you can keep on going, you are alright.” (OA)
Lifestyle Changes Positive	+ “Changed pace”, (OA) + “Get better if I do the things I am supposed to do, like watching what I eat, limit activities”, “Just look out for myself, use good judgment”, (HD) + - “I have to watch what I do. Can’t do what I used to do, don’t try and do as much.” (HD)
Cured/Fixed	+ “Glad it’s gone”, “Glad don’t have discomfort any more.” (OA) + “I don’t think about it. I think it’s cured”, “To me it’s over, heart is better”, “Not like a condition to me. It’s just been something got fixed.” (HD)
Others Worse Off	+ “Others worse off”, “Life is good if you look around”, “See people I feel sorry for.” (HD) + - “Not too bad because I think of other people... Can’t wear pretty shoes...heels hurt hip and back.” (OA)
Fatalistic	+ “Can’t fight it, it’s inevitable... have to die with something”, “Whatever is going to be, is gonna be”, “These things are meant to be.” (HD)+ - “I just feel I have to accept it because there’s nothing I can do. And I feel like I’m on my way out, I feel like it’s my turn to die.”
Limitations/Restrictions	- “Slows you down”, “Can’t do things I want to do”, “...have to go lay down and bare whatcha have.” (OA)+ - “Ain’t nothing I can do that I used to could do”, “Makes me feel weak, restricts everything I do”, “Limitations to what I can do.” (HD)+ - “...as you grow older you lose the mobility that you have when you’re young... lived 83 years had a very good life so I have no complaints coming.” (OA)
Pain	- “Pain, had enough”, “The pain drives me nuts”, “...something you can’t live with when it starts hurtin,” (OA) + - “It’s pain. It’s mind over matter and I just have to keep going... have to keep on doing for yourself.” (OA)
Lifestyle Changes Negative	- “Not the person you used to be”, “Looked at myself different... had to be more careful about my lifestyle”, (HD)+ - “Something that happened and I go on...I have a very mediocre life right now...going out is too much pain...too much effort...so I don’t do it.” (OA) + - “Restricts every-thing you do, it changes your lifestyle... a lot of things that you can do, don’t give up.” (HD)
Psychological Effect	- “Helpless”, “Sometimes I feel sorry for myself, “Makes me feel sad”, “It’s depressing”, “Makes you mad....” “Let down, wondering why it happened to me? (OA) -...makes you feel low...” “I feel useless”, “I feel very upset over it, and I’m worried.” (HD) + - “I feel helpless at times... things I’d like to do...but your arthritis limits you to a lot of things that you like to do...it doesn’t depress me, I don’t be depressed, cause I can always find something to do.” (OA) + - “I don’t like it. It took me a long time to accept it...so I guess I do have heart disease... psychologically it bothers me...” (HD)

* + = Positive; - = Negative;

+ = Combined IHD=Ischemic Heart Disease; OA=Osteoarthritis