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Chronic Illness Self-care and the Family Lives of Older Adults: A Synthetic Review Across Four Ethnic Groups

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Abstract

The purpose of this paper is to integrate the literature on family and social ties among older ethnic minority men and women with the literature on chronic illness self-care among elders in these groups, in order to increase understanding of social influences on self-care behavior, raise questions for future research, and inform culturally appropriate interventions to maximize the health-promoting potential of social relationships. The paper presents demographic and chronic illness prevalence information, and then summarizes literature about patterns of chronic illness self-care behaviors for older African-Americans, Latinos, Asian-Americans, and American Indians in the U.S. For each group, the sociological literature about residential, cultural, and socioeconomic patterns, family lives, and other social ties is then reviewed, and the self-care literature that has accounted for these patterns is discussed. Finally, six themes are outlined and related questions are identified to further illuminate the social context of older adults' chronic illness self-care.

Keywords

Chronic illness; Ethnic minorities; Family; Older adults; Self-care; Social ties

Although living with chronic illness is a reality for the majority of older adults in the United States, there are significant disparities in chronic illness prevalence across racial and ethnic groups (NCHS 2006). Furthermore, racial and ethnic minorities experience greater complications and higher death rates from most chronic illnesses (NCHS 2006; Harris 2001). To reduce these disparities in chronic illness outcomes, we need to better understand how members of these groups live with and manage chronic illnesses, in order to design effective intervention strategies that will enhance chronic illness outcomes (Becker and Newsom 2005).

Self-care behaviors, defined as "the range of health and illness behaviors undertaken by individuals on behalf of their own health" (Dean 1992), play a crucial role in enhancing quality of life and active life expectancy among older adults (Ory and DeFriese 1998). This is particularly true for chronic illness self-care behaviors, which often involve regimens of

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medication taking, physical activity, dietary and weight management, and specific disease-related behaviors (Clark *et al.* 1991; Lorig and Holman 2003). Adherence to chronic illness self-care regimens and behaviors is far from ideal (Glasgow *et al.* 2000); thus, a thorough understanding of the factors that influence chronic illness self-care has important implications for older adults' well-being. Little attention has been paid to racial/ethnic minority populations in the chronic illness self-care literature, especially among older adults (DeFriese *et al.* 1998; Becker *et al.* 2004), nor to racial variation in self-care behaviors (Silverman *et al.* 2008). However, the limited studies suggest racial/ethnic differences in the underlying determinants of self-care behaviors, including knowledge (Becker *et al.* 1998), attitudes regarding responsibility for health and illness management (Becker *et al.* 1998), philosophy of illness (Becker and Newsom 2005), cultural influences (de Groot *et al.* 2003), and spiritual practices and beliefs (Samuel-Hodge *et al.* 2000).

The social context within which older adults attempt to manage their chronic illnesses is important but not well understood (Clark 2003; Stoller 1998). Chronic illness self-care occurs within a network of family and friends who play important roles in facilitating or impeding the self-care process (Becker *et al.* 1998; Berkman and Glass 2000; Gallant 2003), but there is little knowledge as to how these influences operate for specific race/ethnic groups, each of which has its own patterns of close, interpersonal relationships (Gallant *et al.* 2007; Silverman *et al.* 1999). Increasing attention is being paid to the context of self-care among diverse populations, as evidenced by the recent special issue in the *Journal of Cross-Cultural Gerontology* focusing on cultural variations in self-care strategies (Silverman 2008). The need to better understand how context and culture influence self-care behaviors has also been identified (Ory 2008). The purpose of this paper is to contribute to that growing conversation by integrating the literature on family relationships and social ties among older ethnic minority men and women with the literature on chronic illness self-care among elders in these groups, in order to increase our understanding of self-care behavior, raise useful questions for future research, and enhance our ability to design culturally appropriate interventions to maximize the health-promoting potential of social relationships.

In this integrative review, we first summarize what is known about patterns of chronic illness and self-care behaviors for women and men in each of four racial/ethnic groups in the United States: African-Americans, Latinos, Asian-Americans, and American Indians. For each group, we then summarize knowledge about residential, cultural, and socioeconomic patterns, family lives, and other social ties from the sociological literature on racial/ethnic families, demography, and race-ethnicity. We discuss the extent to which the self-care literature on each group has taken cultural and family patterns into account. We then draw implications for how combining these two bodies of knowledge can facilitate the understanding of patterns of self-care among older adults with chronic illness in specific race/ethnic groups.

Because we are drawing from broad, diverse literatures, this is not an exhaustive, systematic review of every relevant study. We identified literature to review as follows: To identify literature related to cultural context and social relationships among each ethnic minority groups, we drew on major review articles from the sociological literature on racial-ethnic families as well as selected empirical studies cited in those reviews and elsewhere. To identify literature related to the social context of chronic illness self-care, we searched the Medline and Psycinfo databases, using search terms that included chronic illness/chronic disease; older adults; self-care/self-management; social networks/social support/social ties. We also used the reference list of relevant articles to identify other articles. Because of the relatively small number of studies that focus on chronic illness self-care among older adults in these racial/ethnic groups, we attempted to include all relevant articles that had a major focus on this topic. However, because of the abundance of literature focusing on family relationships and social

ties among older ethnic minority men and women, we included only the most representative articles in each area in this discussion. Thus, this portion of our review is necessarily selective.

African Americans

African-Americans make up approximately 12% of the total U.S. population, and are projected to remain around 13% through the middle of the current century (Riche 2000). From a population that was roughly one-fifth of those counted in the first U.S. Census in 1790 (Riche 2000), their share of the total gradually declined as slavery was made illegal and other groups immigrated in large numbers (Kent 2007). In more recent decades there has been a resurgence of Black immigration, with the foreign share of U.S. Blacks increasing to 8% by 2005. Nearly two-thirds of foreign-born Blacks were from Caribbean or other Latin American countries and nearly one-third were from Africa (Kent 2007).

Patterns of chronic illness and self-care

Older African Americans tend to have relatively higher rates of chronic illness than other race/ethnic groups. As illustrated in Table 1, they have the highest rates of hypertension compared to all other race/ethnic groups, higher rates of diabetes in comparison to Whites and Asian Americans, and higher rates of arthritis in comparison to Whites, Latinos, and Asian Americans. In addition, older African Americans are more likely to rate their own health as fair or poor than older adults in other racial/ethnic groups.

Middle-aged and older African-Americans with chronic illness engage in substantial illness management self-care, although the use and type of self-care activities varies by illness (Silverman *et al.* 1999; Becker *et al.* 1998). For example, Silverman and colleagues (1999) demonstrated that African American older adults with pulmonary diseases or arthritis are more likely to use healthy lifestyle practices (e.g. diet modification, exercise), and less likely to modify their environment than are older Whites; on the other hand, African Americans with diabetes are less likely to monitor their illness but more likely to exercise than are older Whites, while those with heart disease are less likely than older Whites to use exercise as a self-care strategy. Harris (2001) also documented lower rates of blood glucose self-monitoring among African Americans. Among women with hypertension, African Americans are more likely than Whites to consume recommended amounts of fruits and vegetables, but less likely to exercise (Zhao *et al.* 2008). Among older adults with arthritis, the rates of performance of optimal self-management seem to be equivalent for African-Americans and Whites (Albert *et al.* 2008). In addition to traditional self-care behaviors, older African Americans are somewhat more likely than older Whites to use complementary and alternative self-care strategies (Popoola 2005; Boyd *et al.* 2000; Schoenberg *et al.* 2004), and more likely to use food remedies and other home remedies, both for diabetes self-care and for general use (Arcury *et al.* 2006a)

Older African Americans are generally knowledgeable about illnesses and illness management, and tend to hold beliefs about their responsibility with respect to illness management and adherence with physician recommendations that are consistent with the mainstream biomedical model that underlies health care in the U.S. (Becker *et al.* 1998; Ogedegbe *et al.* 2004). However, some studies of older African Americans with diabetes indicate lack of knowledge and misconceptions about diabetes management (Sarkisian *et al.* 2005) and ambivalence and uncertainty about proper treatment (Chin *et al.* 2000).

Cultural context and social relationships

Older African-Americans experience higher poverty rates and lower life expectancies than do whites (Tucker *et al.* 2004). Due in part to the gender gap in life expectancy, more older Black women than men are unmarried and live with others or alone (Peek *et al.* 2004). Black

households tend to have "permeable boundaries" and more frequent transitions (Dilworth-Anderson 1992; Hays and George 2002; Peek *et al.* 2004). Black elders are also are less likely than whites to be institutionalized (Dilworth-Anderson *et al.* 2005); they have stronger expectations for intergenerational co-residence and for filial responsibility than do older whites (Burr and Mutchler 1999; Lee *et al.* 1998).

Older Blacks are more likely to live with a child or grandchild (Cohen and Casper 2002; Goldscheider and Bures 2003; Peek *et al.* 2004) and care for grandchildren (McAdoo 1998; Perry 1999; Tucker *et al.* 2004), perhaps affecting both their economic status (Minkler and Fuller-Thomson 2005) and their own self-care (Dancy and Ralston 2002). Studies of informal support may underestimate that provided in Black families, because of the role of co-residence (Sarkisian and Gerstel 2004; Silverstein and Waite 1993).

Social support networks of African American families have been described as resilient, flexible, and resourceful (Barker *et al.* 1998), and must be understood in historical context (McAdoo 1998; Becker and Newsom 2005). These ties, while crucial for families in economic need, persist among upwardly mobile families as well (Ellison 1990). However, these networks may be declining (Jarrett and Burton 1999), and Black elders may increasingly need to rely on combinations of family and formal supports (Roschelle 1997).

Older Black women have larger, more intricate social networks than older Black men, with children, especially daughters, as key members (Barker *et al.* 1998; Scott and Black 1999) and potential caregivers (Roth *et al.* 2007). Men's contact with adult children is particularly vulnerable if they are not married to the child's mother (Barker *et al.* 1998; McAdoo 1998) or live alone (Spitze and Miner 1992). Generally, however, adult children are key sources of care for Black elders (Laditka and Laditka 2001; Peek *et al.* 2000; Taylor 1986).

There has been less research attention to friendships of older Blacks than to their family ties. While they prefer kin as informal helpers, friends provide socioemotional support and thus may complement help from kin (Becker *et al.* 2004; Taylor and Chatters 1986). Nonkin may also be incorporated into helping networks as "fictive kin" (Scott and Black 1999). Black women frequently exchange services such as child care with friends (Ellison 1990).

Churches play a central role in the Black community (Becker and Newsom 2005; Cummings *et al.* 2003; Taylor and Chatters 1986), providing spiritual comfort and social resources (Elwert and Christakis 2006) as well as help to elders (Krause 2004; Williams and Dilworth-Anderson 2002). The Black church has been described as "quasi-family" (Scott and Black 1999). Older African Americans are more religious than whites (Taylor *et al.* 2007), with women more involved in the church than men. Religiosity increases the size and density of individuals' social networks, and the quantity of social support received (Cummings *et al.* 2003; Ellison and George 1994; McIntosh *et al.* 2002), perhaps helping to explain lower levels of formal service utilization among older Blacks (see Miner 1995).

Self-care in social-cultural context

Cultural values and traditions have important influences on chronic illness self-care among African American adults, although this area is under researched (Becker *et al.* 2004). Becker and Newsom (2005) have linked a strong cultural value on autonomy and independence to a cultural history that involves high levels of resilience and independence in response to racism. Cultural traditions related to spirituality, social support, and nonbiomedical healing have potentially important implications for chronic illness self-care that are neither well understood, nor well-utilized in intervention approaches (Becker *et al.* 2004). For example, among middle-aged African Americans with diabetes, those with greater traditional cultural orientation and

cultural mistrust were less likely to have diets consistent with mainstream medical recommendations (de Groot *et al.* 2003).

Spiritual belief systems can influence one's approach to illness management (McAuley *et al.* 2000). In general, among African Americans, cultural traditions of spirituality and belief in God are important for adjusting and coping with disease (Samuel-Hodge *et al.* 2000), and are perceived as facilitating self-care (Becker *et al.* 2004; McAuley *et al.* 2000). However, as Polzer and Miles (2007) illustrate, a subset of African Americans relinquish their health to God as healer, rendering self-management irrelevant.

Studies examining social network influences on chronic illness self-care among African Americans indicate unique aspects of this relationship. For example, while the need for help from others was comparable among older Whites and African Americans with various chronic illnesses, African Americans reported *receiving* less help from others with self-care activities (Silverman *et al.* 1999). Similarly, Jennings (1999a) reported that older African Americans with chronic illnesses are less likely than White elders to utilize their available social supports, even though they tend to have a larger number of people available to help them, and even though the vast majority report talking to family members about their illness (Jennings 1999b). When older African-Americans utilized their support networks, help tended to involve transportation, encouragement for health behaviors such as diet and exercise, advice, and monitoring symptoms; however, the desire for independence and autonomy tended to "trump" needs for help, and was the main reason for not activating support networks (Jennings 1999a, b).

The amount and type of help received from others varies by illness. For example, both older Whites and African Americans with heart disease reported receiving a lot of self-care-related help, but African Americans reported receiving less help with diet-related needs (Silverman *et al.* 1999). In the same study, older African Americans with diabetes reported receiving much less help overall than did older Whites with diabetes (Silverman *et al.* 1999).

Similar to White older adults, support for chronic illness self-care comes from a variety of sources, but daughters and other female family members tend to be the most common source of help (Samuel-Hodge *et al.* 2000). Adult children are often the source of reminders, and both kin and close friends provide emotional support (Becker *et al.* 2004). Gallant and colleagues (2007) reported both positive and negative social network influences among both African-American and White older adults for disease management (medication management, dietary activities, physical activity, and health care appointments); illness-related decision-making; and psychosocial coping. In general, they reported many more positive than negative social network influences, and more negative influences from family members than from friends, with what was termed the "church family" more salient among African-Americans.

As indicated earlier, network ties stemming from church membership and support from church members is particularly important among this group (Anderson *et al.* 2000). Church attendance has been linked with higher levels of health screening behaviors among those with chronic illnesses (Aaron *et al.* 2003), and with maintenance of good health behaviors and more social relationships among older adults in general (Strawbridge *et al.* 2001).

Studies support a positive influence of social support on self-care behaviors. For example, among middle-aged to older African American adults with diabetes, social support is positively associated with health promoting behaviors (McDonald *et al.* 2002). Middle-aged and older African Americans with hypertension perceived family support, including reminders, seeing others take medication, and family member approval, as facilitating medication adherence (Ogedegbe *et al.* 2004). However, there is a negative aspect to social relationships as well. Others' lack of understanding sometimes limits the helpfulness of their attempts at emotional

support (Carter-Edwards *et al.* 2004), and lack of knowledge among family members is perceived as a barrier to self-care activities (Sarkisian *et al.* 2005).

The high cultural value placed on giving support to others and to reciprocity also has important implications for self-care and for receiving help for self-care among this group. Being part of a large extended family network does not necessarily equate with receiving a lot of support, but rather carries with it a strong expectation for providing support to others (Samuel-Hodge *et al.* 2000). The multi-caregiver role is a particular barrier for diabetes management among middle-aged and older African American women, as is providing care for grandchildren (Carter-Edwards *et al.* 2004; Samuel-Hodge *et al.* 2000, 2005; Sarkisian *et al.* 2005). Whether the multi-caregiver role is perceived as a barrier seems to be related more to the number of people in a household, than to the number of support recipients (Samuel-Hodge *et al.* 2005). Consistent with a strong cultural value of independence and control, older African Americans with chronic illness perceive themselves as "participating in a mutual aid system in which they saw themselves as primarily on the giving, rather than the receiving, end" (Becker and Newsom 2005, p.217). In a related vein, a strong cultural tradition that places the family first often translates into placing family needs over self-care needs (Samuel-Hodge *et al.* 2005).

Latinos

Latinos are currently the largest minority group in the U.S., expected to be 15% of the population in 2010 and 25% by 2050 (Riche 2000). They have grown rapidly in recent decades (Hayes-Bautista *et al.* 2002) due to immigration and fertility rates (Halgunseth 2004), with around one-third of the current population foreign-born (Riche 2000). Mexican-Americans are the largest Latino subgroup, followed by Puerto Ricans and Cubans (Carter-Pokras and Woo 1999; Halgunseth 2004). However, Latino elders are underrepresented in discussions of both minority elders and Latino families (Berkman and Gurland 1998; Hurtado 1995).

Patterns of chronic illness and self-care

As illustrated in Table 1, older Latino adults have higher rates of diabetes than Whites and Asian Americans. Although their rates of other chronic illnesses are comparable to other groups, they are more likely to rate their own health as fair or poor.

Chronic illness self-care activities among middle-aged and older Latino adults tend to be somewhat less prevalent than among older Whites. For example, middle-aged and older Latinos infrequently reported self-care practices other than taking medications (Becker *et al.* 1998); Hispanics with diabetes are less likely than Whites to use diet and exercise as self-care strategies (Coronado *et al.* 2007); among Mexican Americans, there is a lower prevalence of blood glucose self-monitoring (Harris 2001); and physical activity levels are lower among Hispanic women with hypertension, as compared to Whites (Zhao *et al.* 2008).

Complementary and alternative medicine (CAM) use is relatively high in this population. Schoenberg and colleagues (2004) report that 50% of Hispanic Americans with diabetes report using CAM, the highest rate among four racial and ethnic groups studied. Hispanic older adults are also the second most common users of herbal remedies (after Asian Americans), with 24% reporting their use. In fact, among this group, the diagnosis of chronic illness is sometimes delayed because of long reliance on alternative healing practices (Becker *et al.* 1998).

A few studies have indicated that knowledge levels about chronic illness and its management tend to be lower among Hispanic adults as compared to other ethnic groups. (Becker *et al.* 1998; Carbone *et al.* 2007; Sarkisian *et al.* 2005). In addition, Latinos' views about health and illness management tend to diverge from the U.S. biomedical model (Becker *et al.* 1998) to integrate both biomedical explanations and traditional and folk beliefs (Hatcher and

Whittemore 2007). Becker and colleagues (1998) demonstrated that Latinos' understanding of their role in illness management is limited to taking medications, and that cultural views about illness may conflict with the mainstream notion of individual responsibility for illness self-care. Especially among older Latinos, illness management is perceived to be a family responsibility, and not the responsibility of the individual with the illness (Becker *et al.* 1998).

Cultural context and social relationships

Latinos face economic challenges and many lack health insurance (Carter-Pokras and Woo 1999). Older men are more likely than women to be married, and Latinos of all ages are more likely to live in multigenerational households than Whites (Berkman and Gurland 1998; Cohen and Casper 2002; Sarkisian *et al.* 2007), in part due to economic patterns (Lee and Aytac 1998). Thus, Latino elders are less likely than Whites to live alone or in institutions (Burr and Mutchler 1999), although Puerto Ricans have slightly higher rates of single living than do Mexican-Americans (Zsembik 1993) and residence varies by immigration history for Mexican-Americans (Blank 1998). Latinos express stronger support than Whites for the provision of intergenerational housing (Burr and Mutchler 1999) although most elders may prefer to live independently (Beyene *et al.* 2002).

Family and extended kinship ties are central for Latinos (Becker *et al.* 2003), with elders occupying a respected role within Mexican-American family systems (Beyene *et al.* 2002; Martinez 1999). Contact with, and assistance from, adult children (Dietz 1995) are higher than among Blacks or Whites (Lee and Aytac 1998; Wong *et al.* 1999). English language usage can present challenges to Latino elders, particularly immigrants (Beyene *et al.* 2002; Hayes-Bautista *et al.* 2002), increasing the role of family networks (Gelman 2002). Involvement in a social network and the transmission of cultural values to their families shapes older Latinos' perceptions of aging and sense of well-being (see Beyene *et al.* 2002 on Mexican-Americans; Freidenberg 2000 on Puerto Ricans).

Substantial numbers of Mexican-American elders provide child care and more give than receive intergenerational financial help (Dietz 1995). More generally, Mexican American women are more likely than Whites to provide child care and household assistance to extended family members (Sarkisian *et al.* 2007). In addition to a strong sense of familism (Beyene *et al.* 2002), Latinos assign important roles to chosen family such as godparents (Halgunseth 2004).

Mexican-American elders' health and their attitudes toward aging are strongly influenced by religiosity (Beyene *et al.* 2002; Hill *et al.* 2005), and older Latinos receive social support from religious leaders (Martinez 1999). Apart from the centrality of church, family, and godparents, less is known about the role of other members of the social networks of Latino elders, such as neighbors and other friends.

Self-care in social-cultural context

Cultural expectations about traditional gender roles may challenge illness self-care, particularly for diet-related behaviors. Hispanic males with chronic illness are typically dependent on women, who hold central roles in the household and for meal preparation. For women with chronic illness, their diet-related self-care needs tend to take a back seat to family needs and preferences (Carbone *et al.* 2007).

Cultural traditions of spirituality and religion also impact illness self-care. Religious beliefs are part of Hispanic explanatory views about illness causation and its treatment (Hatcher and Whittemore 2007) and positive self-care behaviors are attributed to God's help (Carbone *et*

al. 2007). In addition, Latinos with arthritis report high levels of religious coping strategies (Abraído-Lanza *et al.* 2004).

Among older Latino adults, the extended family is perceived as the primary support group (Wen *et al.* 2004a), and plays an important role in supporting illness management, and providing motivation and collective strength (Carbone *et al.* 2007). Support from family is particularly important to self-care among Latino adults with diabetes (Chesla *et al.* 2003; Wen *et al.* 2004a, b). Family members' lack of knowledge about diabetes is perceived as a barrier to self-care (Sarkisian *et al.* 2005), and being around others who are eating and drinking discouraged foods is perceived as a common barrier to dietary management (Wen *et al.* 2004a).

There also appears to be a gender difference among Hispanics in family support, particularly for diet. Men with diabetes perceive greater levels of family support (Brown *et al.* 2000) while responsibilities to the family, particularly around meal preparation, pose a challenge to women with their own dietary self-care needs (Carbone *et al.* 2007).

Although research about family support for illness management among this group is somewhat limited, findings that Latino older adults hold different cultural views about individual versus family responsibility for illness management, as compared to African American and White elders, suggest that examining the role of social network members in this population subgroup may be a ripe area for research (Becker *et al.* 1998).

Asian Americans

Asian Americans constituted 4% of the U.S. population around the turn of the twenty-first century and are projected to compose 9% by 2050 (Riche 2000). They are a highly diverse group, comprised of 28 subgroups with varied immigration histories dating from the latter half of the nineteenth century to the period since the 1965 immigration reform (Ishii-Kuntz 2004). Currently over half are foreign-born (Riche 2000). Older Asian Americans include those who are second or later generation and those who immigrated recently to join adult children (Ishii-Kuntz 1997). Although aspects of Asian American culture that are consistent with mainstream U.S. values have been used to explain their socioeconomic success, there are also kinship values that tend to set them apart from the mainstream (Ishii-Kuntz 1997).

Patterns of chronic illness and self-care

Asian American older adults have lower rates of many chronic illnesses, as compared to other race/ethnic groups. The prevalence of heart disease and arthritis is relatively low, compared to other groups. However, as illustrated in Table 1, the prevalence of hypertension among this group is higher than among Latinos and Whites.

Relatively little literature focuses on self-care among older Asian Americans with chronic illness. We found no studies about the prevalence of chronic illness self-care behaviors in population based samples, although Becker and colleagues (1998) report that among their sample of middle-aged and older Filipino-Americans, self-care practices were common, and emphasized diet, exercise, and taking medications. A small body of literature documents the relatively high use of complementary and alternative medicine among older Asian Americans. Data from the National Health Interview Survey for White, African-American, Hispanic, and Asian adults illustrate that Asian older adults are the most frequent users of complementary and alternative medicine, with 49% reporting their use, compared to an average of 28% overall (Arcury *et al.* 2006b). Herbal remedies are especially common, with 28% reporting their use, compared to an average of 12% overall (Arcury *et al.* 2007). Among older Chinese adults, two-thirds reported using both traditional Chinese medicine, most often herbs and herbal formulas,

and Western medicine; the use of traditional Chinese medicine was highest among Chinese immigrants, as compared to Asian immigrants of different origin (Lai and Chappell 2007).

Cultural attitudes and beliefs facilitate self-care and self-management behaviors among Asian Americans. The traditional emphasis on self-discipline contributes to the positive effect of self-management interventions (Chan *et al.* 2005), and the limited evidence available suggests that knowledge about illness is fairly good (Becker *et al.* 1998), and attitudes about self-care behaviors tend to be positive (Lin *et al.* 2007). Evidence regarding the consistency of Chinese health beliefs with the U.S. biomedical model is somewhat mixed. Among a sample of Filipino Americans, Becker *et al.* (1998) found that views about chronic illness management tend to correspond to mainstream Western biomedical views; however Zhang and Verhoef (2002) report that Chinese immigrants with arthritis view traditional Chinese medicine as more effective than Western medicine at treating chronic illness.

Older Asian Americans tend to place a high priority on health, and on individual responsibility for good health. However, the responsibility for maintaining one's health is part of a broader responsibility to one's family and social group (Becker *et al.* 1998).

Cultural context and social relationships

Older Asian Americans are much more likely than Whites to live with family members other than (or in addition to) a spouse, but patterns vary by national origin and immigration period. For example, the majority of Japanese-American elders live with a spouse or alone (Phua *et al.* 2001). However, in comparison to Anglo Whites, both Chinese and Japanese elders are more likely to live in extended family households even if married (Kamo and Zhou 1994; see also Burr and Mutchler 1993). The majority of unmarried older Asian Indians, Filipinos, and Koreans live with other family members, as do almost half of Chinese; Phua *et al.* (2001) argue for the importance of ethnic context in mediating how other factors affect living arrangements.

Asian-Americans tend to value dependence on the family group, responsibility for others including elderly parents, and obedience to parental authority (Ishii-Kuntz 1997, 2004; Kim and McHenry 1998; Wong *et al.* 2006). However, for those elders who move to the U.S. to join their adult children, core values may be modified in response to children's financial independence and patterns of dual employment among the adult child generation. Wong *et al.* (2006) analyzed focus group data for older Chinese and Korean Americans in San Francisco, describing their values as "bicultural." Older parents try to be financially independent to avoid burdening their children, made possible by Social Security and government housing. They are keenly aware of the shift in their centrality to the family and tend to avoid offering advice lest it be seen as criticism. Similarly, a study of older Japanese Americans found a preference for living near children rather than with them, although finances more often led to intergenerational co-residence (Osako and Liu 1986).

Lin and Liu (1993) point to important differences between the values of Chinese immigrants (and their adult children) and those of American culture. Based on vignette data, they find strongly held Chinese values, in some cases stronger among the adult children than the parents. The Chinese culture places a higher value on the parent-child dyad than the husband-wife one, and on interdependence than independence. As they put it, "…whereas American parents struggle to be independent to maintain their self-esteem, the Chinese maintain their self-esteem by having someone to depend on…" (p. 274; see also Osako and Liu 1986).

Ishii-Kuntz (1997) argues for the importance of measuring cultural attitudes rather than assuming the values held by individual Asian Americans. He examines variations among three national origin groups in their attitudes and structural circumstances. He finds Koreans to have the highest levels of support to older parents, and attributes this both to their more recent arrival,

and to the younger ages of grandchildren needing care, allowing for reciprocity of help between adult children and their older parents.

Self-care in social-cultural context

The social networks of older Asian Americans play an important role in chronic illness self-care behaviors. Family members tend to be engaged in promoting healthy behaviors, such as exercise (Becker *et al.* 1998; Lin *et al.* 2007). Satisfaction with the receipt of social support is linked to better dietary and exercise behaviors among those with diabetes (Anderson *et al.* 1995), and greater social support is associated with greater use of traditional Chinese medicine (Lai and Chappell 2007). However, research also supports the idea that older Asian immigrants tend to rely less on family members, particularly sons and daughters, than cultural values of filial piety would predict, and that this group demonstrates more independence in taking care of their health than previous generations (Pang *et al.* 2003).

Friends also play an important role for this group; older Chinese adults rely on neighbors and friends, in addition to family, for health-related help, and utilize this broad social network for help with transportation, language assistance, and decision making (Pang *et al.* 2003). Chinese Americans with arthritis tend to rely on friends, instead of relatives, for information about both Western and traditional Chinese medicine (Zhang and Verhoef 2002). Among older Samoan women, kin networks were found to be associated with chronic-illness related health behaviors, and non-kin networks were associated with broader lifestyle behaviors, like exercise and losing weight (Levy-Storms and Lubben 2006). Pang *et al.* (2003) examined the pathways to care of elderly Chinese and found that this group would rely on self-care first, and then seek help from their spouses. Friends and neighbors, as well as adult children, would be turned to next. Only when conditions worsened and became more serious would doctors be consulted.

American Indians

The American Indian population, constituting under 1% of the total U.S. population, has tripled in size since their nadir around 1900 (Riche 2000), and the older adult population is particularly fast-growing (Sandefur *et al.* 1996). Although there is enormous diversity in languages and tribes, there are also commonalities in their worldviews (Garrett and Garrett 1994). Kawamoto and Cheshire (2004) discuss the multiple meanings of the term “seven generations,” referring to the impact of one’s behavior on the next seven generations, as well as one’s embeddedness in the three generations before and after one’s own. This view has been crucial in maintaining Indian culture, given the history of government attempts to eradicate these peoples and their cultural continuity (Rogers 2001), as well as large scale movements to urban areas (Stubben 2001).

Patterns of chronic illness and self-care

The American Indian population experiences a significant burden from chronic diseases, although national-level data are limited (Galloway 2005). As illustrated in Table 1, they have the highest rates of heart disease, diabetes, and arthritis, as compared to other groups. Population-based prevalence rates of hypertension among older American Indians are not available, but several studies suggest that rates of hypertension among American Indians in general are comparable to that among African Americans (Galloway 2005).

Little research speaks to chronic illness self-care and its determinants among American Indians of any age, and information on the prevalence of chronic illness self-care behaviors in this population is scarce. However, a recent study among women with hypertension reported that levels of physical activity were lower among American Indians than among other racial and ethnic groups (Zhao *et al.* 2008). In addition, among older American Indians in general, rates

of smoking and of physical inactivity are higher than among older Whites (Denny *et al.* 2005).

There is a strong emphasis on traditional healing practices (Garrett and Garrett 1994) often used in concert with Western health care systems (Smyer and Stenvig 2007). For example, Arcury *et al.* (2006a) document that the use of home remedies, some involving food, is more common among Native American rural older adults with diabetes than among Whites, and that these remedies are used for both general purposes and diabetes-related self-care.

Cultural context and social relationships

Research knowledge on American Indian families is sparse, both due to limited resources for such research and to the diversity of tribal cultures (Kawamoto and Cheshire 2004; Stubben 2001). However, it is clear that extended families are the key element of tribal culture (Stubben 2001) with decisions influenced by family interactions (Smyer and Stenvig 2007). Both households and families tend to be larger than the U.S. average (Schwede and Blumberg 2005).

American Indian values include a strong emphasis on identity with extended families and larger groups, respect for elders, and on responsibility for family and group members (Baldridge 2001; Garrett and Garrett 1994). Elders, particularly women, play a central role, both in maintaining cultural norms and in caring for children and grandchildren (Cheshire 2001; Rogers 2001). They may use their limited financial resources such as Social Security to provide housing and support to younger family members (Bahr 2007; Baldridge 2001; Letiecq *et al.* 2008). For this and other reasons, older persons are at risk for economic hardship. They are cared for by younger members of the family and the tribe, particularly by adult women. However, their long term care needs may strain the resources of families who try to care for them at home but who also have very limited economic capacity (Fitzpatrick *et al.* 2008; Manson 1989).

Elements of American Indian culture may also influence how elders deal with or report illnesses. They tend to view the needs of family or community as more important than their own (Smyer and Stenvig 2007), and the concept of “tolerated illness” implies that the needs of others should take precedence over one’s own personal health needs (Moss 2005). Physical health may also rank below spiritual or emotional health in priority (Goins *et al.* 2005). Sickness is viewed holistically, as an indication of imbalance among mental, spiritual, emotional, physical and social influences (Smyer and Stenvig 2007).

Self-care in social-cultural context

Evidence is mixed as to whether a dependence on traditional culture is associated with better or worse health protective behaviors (Canales 2004). However, as Perrone *et al.* (1989) indicate, traditional culture values partnership in the patient—provider relationship, or “a connectedness between the healer and the patient” (p. 4). This traditional value, is consistent with the conceptualization of ideal chronic disease self-management, which envisions a mutually cooperative patient-provider relationship in chronic illness care.

Although a strong cultural value on self-reliance has been demonstrated among the Cherokee (Lowe 2002), traditional attitudes toward self-care reflect the value of self-care as a means of achieving good health for both individuals and their families (Canales 2004). That is, self-care is not viewed as a self-interested competitor to care of others, but rather, as a complement to care of other family and community members (Canales 2004).

Discussion

Limitations of previous research

The literature on chronic illness self-care among older adults in minority ethnic groups is limited. This is both ironic and problematic, given that rates of chronic illness are mostly higher in these groups than among majority older adults. Among the groups discussed here, African Americans have received the most research attention, both in the literature on chronic illness self-care and the literature on the families of older persons. There is a paucity of literature on Latinos and even less on Asian-Americans and American Indians; the latter tends to be based on small samples, due to the challenges of studying these groups. In addition, as Silverman and colleagues (2008) have pointed out, comparisons across existing self-care research are further complicated by the differences in how self-care behaviors are categorized and measured.

We need further research focusing on each of these groups, however, in order to understand the role of the family and social context in chronic illness self-care. There also tends to be less research on men than on women, both because men tend to be less open to revealing personal matters to researchers, and because family researchers have sometimes tended to ignore older men's role in families, viewing mothers and grandmothers as more central. Further, men tend to have shorter life expectancies than women, and among these subgroups all but Asian Americans have shorter life expectancies than European Americans. Thus, studies of older persons may yield fewer men due to earlier death or disability. Given these demographic facts and the earlier onset of chronic illnesses, research in this area should expand its focus to include both middle aged and older men and women in these ethnic groups.

The literature on the social context of chronic illness self-care is also limited in several other ways. For example, studies tend to focus on a specific illness, despite the fact that older persons often have multiple illnesses, with some common and some unique self-care regimens. Additionally, studies of the role of other persons in self-care have tended to focus on specific others, such as a particular child or friend, as have studies of elder caregiving. A focus on the entire social network and its cultural context would provide a much more comprehensive understanding of those social influences as well as the mechanisms through which they occur.

Synthetic themes and questions from combining literatures

Research on minority elders must be framed in the context of each subgroup's complex history and internal diversity. Historical experiences including immigration, enslavement, decimation, discrimination, and cultural devastation imply complex cultural differences, including some that overlap in very broad terms. For example, each group places a high value on familism and family support, due in part to scarce resources, inadequate formal supports, or distrust of formal sources. Among African Americans and American Indians, there is also suspicion of medical researchers and the health care system due to past abuses (Napoles-Springer *et al.* 2000; Smyer and Stenvig 2007). There are varying degrees of intergenerational obligation among these groups, with each expecting children to assist and care for parents, a value perhaps most strongly held by Asian Americans. In what follows, we outline six themes and related questions that we argue can usefully further our understanding of chronic illness self-care in the social context of older adults.

1. Self care, independence and interdependence—Cultural views of the individual's role in relation to the family or community may have implications for the practice of self care. The theoretical background of chronic illness self-care and self-management is very much rooted in Western ideals of independence, responsibility for self, individual autonomy and self-determination. This is consistent with the African American cultural value placed on

independence and self-reliance, particularly among women. They may tend to be more individualistic, trying to meet their own needs and not wanting to use extended family resources. It is also consistent with the Asian cultural emphasis on self-discipline, although Asian American culture tends to put the needs of the family group above those of the individual. American Indian elders may also tend to put the needs of the family group above those of their own health, with potentially negative consequences for health. But the theoretical basis of chronic illness self-management may be at odds with Latino cultural values of illness management being a responsibility of the extended family, and this may partly account for lower levels of self-care behaviors among Latino older adults. Given this, more attention should be paid to tailoring self-care interventions for this group.

In a related vein, it is possible that older members of some groups will be reluctant to ask for needed help, but for reasons that vary with the group's culture. Self-management programs for all ethnic groups will be more effective if they take into account how ethnic family cultures relate to the concepts of self-care and self-management. For example, African American families may benefit from discussions of how appropriate types of help and support for self-care can be given to elders while still preserving and maintaining the elder's need and desire for independence. Latino families may benefit from chronic illness self-care education that is reframed to incorporate the entire family, in recognition that "self-care" of elders is viewed as a family responsibility, and that capitalizes on the fact that elders hold a respected and secure role in the family. Ethnic minority families in general may benefit from strategies for integrating traditional self-care practices with Western medicine, so that elders are not receiving Western medical advice from their health care providers and traditional advice from families and friends, separately. American Indians might find it useful to discuss how to meet the needs of elder family members' self-care in the context of other family members' needs.

Until self-management educational approaches are framed to recognize and incorporate these cultural differences, standard self-management approaches may be less effective in some groups, and may result in unfair perceptions of individuals being non-compliant with medical recommendations. We suggest that future research can usefully focus on the following questions: To what extent are cultural beliefs consistent or inconsistent with the theoretical foundations of self-management? Do certain underlying assumptions of the self-care concept need to be reframed among groups, like Latinos, who view illness management as a family, not individual, responsibility? How can self-care of elders be encouraged in a context that respects these cultural differences?

2. Patterns of intergenerational support and co-residence—Multi-generational households, as a means of financial cooperation and instrumental or personal assistance, are also more common in each of these groups than among non-Hispanic Whites. These patterns of multi-generational households have important implications for older adults' self-care, although these implications may differ for each group. Older family members are more likely to be cared for at home than are European Americans. Family elders, particularly women, also provide support to younger generations, both through co-residence and through child care or informal fostering of grandchildren. The latter is particularly common among American Indians and African Americans. These patterns of downward assistance create extra challenges for self-care of parents and grandparents.

There is a somewhat prevailing myth in the health literature that African American adults are advantaged in terms of social support because of their relatively larger family and social networks. But research suggests that this perception, at least with respect to help and support for chronic illness self-care among older adults, is overly simplistic. While African American women do tend to have larger social networks than some other groups, comprised of family, friends, religious ties, and fictive kin, this does not necessarily translate into the receipt of more

social support. This is partly because of the strong cultural value placed on independence, which may mean that available social supports are not utilized. This is also due to the multiple demands for caregiving and reciprocity that stem from large networks leading to more responsibility and obligation to others that may interfere with self-care.

Among Asian American families in this country, there is evidence that strong expectations and patterns of filial piety and responsibility to elders are changing. It is unclear in what ways these changes may influence patterns of self-care.

Thus, we pose the following questions for future research: For each group, how does intergenerational co-residence provide a context for support? How do higher rates of intergenerational co-residence influence older adults' self-care, and in what ways is such co-residence a help or hindrance to self-care? To what extent do members of the older generation provide instrumental help and support to adult children and to grandchildren, including full-time informal fostering? In what ways may that downward support affect the ability of older persons to attend to their own chronic illness needs?

3. Gender differences in family roles—There has not been enough attention paid to gender differences in older adult self-care, and the literature suggests that there may be some important gender differences related to the influence of social ties on self-care. Women tend to be family health managers. They may also be more integrated into family networks, and are more likely to be living with members of other generations, while men rely on wives for support. Older African American men may be particularly vulnerable to a lack of social support for self-care, due to their smaller social networks and greater likelihood of living alone. Older African American women may be vulnerable because of caregiving demands placed on them. Among Latinos, traditional gender roles dictate that older men are mostly taken care of by wives, so their diet-related self-care may be completely dependent on the support and management of their wives. For older Latinas, their role as household manager and mealpreparer trumps their own dietary needs. Little is known about gender and self-care among older Asian Americans and Native Americans.

Future research that attends to questions such as these may usefully advance knowledge in this area: How can older women successfully integrate caregiving roles with their own self-care, so that the latter is not disadvantaged? How do traditional gender roles among Asian Americans and Native Americans influence self-care behavior? To what extent is men's self-care hindered when widowhood or divorce leaves them without strong ties to partners or adult children?

4. Relation of traditional healing to family networks—Each of the groups discussed here tend to use complementary and alternative medicine in their self-care to a greater extent than non-Hispanic Whites, particularly among older adults and (for Asian-Americans and Latinos) immigrants. What is not known is the manner in which family members are involved in passing on and supporting these traditions, or in attempting to persuade older family members to adopt Western medical practices or to combine the two. It has also been found that older Asian Americans tend to receive much health-related help from friends, which may translate into more use of traditional medicine strategies.

Thus, for each of these groups, we would suggest that research focus on the interaction between family and other social network members and these traditional practices, such that this knowledge can be used to design effective intervention strategies that incorporate and are respectful of these cultural traditions. For example, what role do family members and friends play in determining traditional medicine use, and does this vary by ethnic group? In what ways are traditional medicine practices complementary or consistent with the standard recommended self-care practices, and in what ways are they divergent? How can common traditional healing

strategies be integrated within self-management education for individuals and family and friends among these groups?

5. Friends and fictive kin—The role of support from friends has been studied less than that of families. However, members of some of these groups also tend to involve friends in kin-like roles in their families, including “fictive” or “created” kin (see Garrett and Garrett 1994 for American Indians) and godparents. As indicated previously, older Asian Americans may be more involved with friends, in part to adjust to lower expectations for filial responsibility in their adopted country, and we need to learn more about how these friendship relations combine with or substitute for those with adult children and other family members.

Useful questions for future research may include the following: To what extent do older members of these race/ethnic groups receive support from friends for their self-care needs, and does this support supplement or substitute for help from family? Are the roles of “fictive kin” more like those of other kin or do they play roles more like those of other friends, which are often complementary to those of kin?

6. Churches and other religious ties—Finally, the role of churches, for African Americans in particular but also for other elders, is integral to that of family networks. Church-based health promotion programs for African Americans have been highlighted as having potential for addressing health disparities (Campbell *et al.* 2007). But church-based friends may represent key social ties that may have a significant influence on self-care. More broadly, spirituality, the role of God as healer, and cultural practices such as traditional healing must be taken into account in any understanding of the family and social context, as such beliefs and practices are passed on through social interaction (Becker *et al.* 2004).

Research questions that might advance the literature in this area include: What is the role of the church and church-based friends in self-care and how might that be incorporated into self-care interventions? How have existing church-based interventions capitalized on the influence or role of church-based social relationships or are churches simply the setting for such interventions? In what ways is the role of church or other religious involvements similar or different for these groups? What is the relationship between church and family support—an integrated network or separate alternative sources?

Conclusion

One way to partially address health disparities in chronic illness outcomes is by improving self-care behaviors (Bierman and Clancy 2001). Of course, focusing on self-care differences as a way to understand health disparities runs the risk of appearing to blame the victim for disparate health outcomes (Gordon *et al.* 2005). We emphasize that self-care behaviors are but one category of many causal determinants of chronic illness outcomes, and don’t intend to imply that improving self-care behaviors is all that is necessary or sufficient to address these significant disparities in chronic illness outcomes. Further, we argue that differences in self-care behaviors are partly attributable to the fact that current approaches to self-care have not adequately incorporated cultural values related to health and illness management, and in this paper, we try to add to knowledge in this area.

Understanding how culturally patterned family relationships and social ties influence self-care will help us learn how to maximize the health-promoting potential of social relationships. Of course, focusing on such micro influences on self-care is only one aspect of the total self-care picture; macro-level influences on self-care, such as the uneven distribution of socioeconomic resources and access to health care among these groups, must also be taken into account, and these will not be addressed through a focus on social relationships.

Health disparities in chronic illness will not be addressed at all by self-management interventions that take a one-size-fits-all approach across different racial and ethnic groups. In contrast, if self-care interventions for older ethnic minority adults are designed to be consistent with traditional values and beliefs and to frame self-care within cultural patterns of family relationships and social support, older adults will be empowered to manage their chronic illness self-care more effectively.

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Table 1

Prevalence of Selected Chronic Illnesses among Older Adults (65+) in Different Race / Ethnic Groups

	White	African-American	Latino	Asian American	American Indian
Hypertension	49%[b]	67%[b]	47[b]	54%[b]	[a]
Heart disease	32%[b]	26%[b]	22%[b]	25%[b]	42%[c]
Diabetes	14%[b]	24%[b]	24%[b]	15%[b]	30%[d,e]
Arthritis	49%[c]	53%[c]	43%[c]	34%[c]	53%[c]
Self-reported fair or poor health	24%[b]	41%[b]	40%[b]	26%[b]	30%[c]

[a] Estimate for older adults not available

[b] Schoenborn et al. 2006

[c] CDC/NCHS

[d] CDC 2003

[e] Among adults aged 55 and older